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Louise A. Reagan

*University of Connecticut - Storrs*, [louise.reagan@uconn.edu](mailto:louise.reagan@uconn.edu)

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# Building a Foundation for Diabetes Clinical Behavioral Research with Incarcerated Persons

Louise Ann Reagan, PhD

University of Connecticut, 2014

Diabetes is a burgeoning problem for the correctional setting and for incarcerated persons with diabetes. Good glycemic control is effective for reducing diabetes related morbidity and mortality. There is abundant research in the community examining factors that influence glycemic control. To improve diabetes care, self-management and outcomes, findings from previous research are being integrated into comprehensive clinical trials and translational research in community dwelling populations. Research of this nature with the incarcerated population is nonexistent.

The purpose of this dissertation is to lay the foundation for developing interventions to improve diabetes self-care management and glycemic control in incarcerated persons with diabetes. To begin this process and achieve the purpose of this dissertation, three papers are presented. The first paper, a research study, examines factors that are associated with diabetes control for incarcerated person with diabetes. To further prepare for intervention research with incarcerated persons with diabetes, the aim of the second article is to analyze the methodological challenges for conducting clinical behavioral diabetes research in the correctional setting. The research study presented in article one will provide the basis for this analysis. Considering known system wide constraints to self-care management within the prison and findings related to the performance of self-care behaviors described in article one, the focus of article three is to discuss a theory based approach for self-care for diabetes in the incarcerated

Louise Ann Reagan- University of Connecticut, 2014

population within the framework of the Rediscovery of Self-Care (RSC). The RSC is a newly developed care model for persons with incarceration experience. Findings from the three articles will be synthesized to formulate a research strategy or recommendations for research to improve self-care management and glycemic control in this population.

Building a Foundation for Diabetes Clinical Behavioral Research  
with Incarcerated Persons

Louise Ann Reagan

B.S.N., Western Connecticut State College, 1980

M.S., University of Connecticut, 1994

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

at the

University of Connecticut

2014

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Louise Ann Reagan

2014

APPROVAL PAGE

Doctor of Philosophy Dissertation

Building a Foundation for Diabetes Clinical Behavioral Research  
with Incarcerated Persons

Presented by

Louise Ann Reagan, B.S.N., M.S.

Major Advisor \_\_\_\_\_  
Deborah Shelton

Associate Advisor \_\_\_\_\_  
Everett Seyler

Associate Advisor \_\_\_\_\_  
Michelle Judge

University of Connecticut

2014

## DEDICATION

I dedicate this dissertation to my wonderful family. To Rick, my husband, for supporting me throughout this process- your love and care carried me through many a night. I truly could not have accomplished this without you by my side.

To Erin, my daughter, and Matthew, my son, for your unconditional love and encouragement throughout all of my educational endeavors and to my mother and father who made me feel as if I could accomplish most things in life with persistence and hard work. I love you all.

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## Chapter I

### Introduction

In 2013, more than 10 million or 144 out of 100,000 people were incarcerated worldwide (Walmsley, 2014). Many of these individuals are from poor and marginalized areas (Dumont, Allen, Brockman, Alexander, & Rich, 2013; World Health Organization [WHO], 2014). The United States has the highest population of incarcerated persons (National National Research Council [NRC], 2014; Walmsley, 2014). Over half of those incarcerated have a mental health problem (James & Glaze, 2006) and many have drug and alcohol use disorders (Binswanger, Krueger, & Steiner, 2009; Karberg & James, 2005). Additionally, incarcerated persons have a high burden of many chronic health problems including asthma, hypertension, and diabetes (Fazel & Baillargeon, 2011; Mallik-Kane & Vischer, 2008; Wilper et al., 2009). Generally, the incarcerated population or those with an incarceration experience are less healthy and have greater health needs than those persons living in the community who have no history of an incarceration experience. Similar to the community dwelling population, the incarcerated population is aging and with that comes increased health problems and chronic illnesses (Loeb & Steffensmeier, 2006; Williams, Goodwin, Baillargeon, Ahalt, & Walter, 2012).

Given the multi-morbidity often seen in the large number of incarcerated persons and the constraints of personal liberties associated with being incarcerated, providing health care to inmates can be costly (The PEW Charitable Trust, 2014) and engaging inmates in their healthcare can be challenging. None the less, inmates do have a legal right to health care that is equivalent to health care provided in the community (Estelle v Gamble, 1976). Efforts are being made to improve health related outcomes and develop evidence based standards of care in correctional health (Binswanger et al., 2009; Loeb & Steffensmeier, 2006; Stern, Greifinger, &

Mellow, 2010). However, translation of evidence based guidelines used in the community population to the prison, although a start, may not produce the most clinically or cost effective approach to improve or ensure the delivery of equitable healthcare for incarcerated persons. Research is desperately needed to examine all aspects of health care and chronic illness management in the prison.

Furthermore, providing evidence based care in the prison will improve the health of the inmate before (s)he re-enters the community. Approximately 95% of inmates are released back into the community (Wang & Wildeman, 2011). And the release rate of prisoners into the community is increasing (Cuellar & Cheema, 2012; West, Sabol & Greenman, 2010). Typically inmates come to prison from socially disadvantaged communities and return to the same communities (NRC, 2014). Stabilizing mental and physical illnesses and engaging inmates in self-care prior to re-entry will not only improve the health and well being of the inmate but also has the potential to improve overall health and decrease health disparities in that community.

### **Defining the Problem**

Diabetes is one chronic illness that the National Commission on Correctional Healthcare [NCCHC] (2013) and the American Diabetes Association [ADA] (Lorber et al., 2013) have adapted community based guidelines for use in the prison. This effort was stimulated by the unique challenges for managing diabetes in the prison and the inmate's legal right to care (NCCHC, 2013). The effectiveness of these guidelines and diabetes care in general is largely understudied. However, diabetes prevalence in the prison has been reported to occur at a similar or slightly less prevalence (Lorber et al., 2013) and at greater prevalence (Wilper et al., 2009) than in community dwelling individuals. Although there are conflicting reports in disease prevalence, it is anticipated that diabetes prevalence in prison will increase (Lorber et al., 2013).



The reasons for this increase are likely multifactorial and include the following: diabetes and obesity are reaching epidemic proportions in the community (ADA, 2013, 2014); diabetes disproportionately affects African American and Latino persons who represent over half of incarcerated population (Dumont et al., 2013; Wang & Green, 2010); older inmates with long criminal sentences who are aging in prison have an increased incidence of developing chronic conditions such as diabetes (Williams, Goodwin, Baillargeon, Ahalt, & Walter, 2012); and obesity and diabetes are increasingly affecting younger people who are at greater risk of coming into contact with the law and being incarcerated (Lorber et al., 2013).

With the predicted rise in diabetes prevalence in the prison, it is imperative that we take action now to develop evidence based approaches to help inmates manage their diabetes. Diabetes requires a high degree of self-care management (AADE, 2014). Diabetes self-management education and support programs are abundant in the community. These have been well researched and take into account a person's needs, goals, experience, beliefs, culture, language, social support and abilities to perform self-care (AADE, 2014). The aim of diabetes self-management education is to help person with diabetes learn how to problem solve, actively engage in their care and perform positive self-care behaviors (AADE, 2014).

Self-care management of diabetes can be especially challenging for the person living with diabetes in prison. Personal vulnerabilities such as cognitive impairment, high prevalence of alcohol and substance abuse disorders and environmental factors of living in a custodial environment, oftentimes in crowded conditions, will have some affect on an inmate's ability to engage in self-care (Shelton, 2011). Preliminary work with inmates with diabetes does suggest that inmates are performing some elements of self-care (Reagan, 2011). However, it is not known with what frequency inmates are performing self-care or the type of self-care behaviors

being performed. Having the ability to effectively self-care manage can improve quality of life and clinical outcomes such as lowering the A1C. Lowering the A1C or improving glycemic control is crucial to reducing morbidity, disability and mortality (ADA, 2014). Many factors are known to affect glycemic control in the community but this knowledge as it relates to an incarcerated population is lacking (Reagan, 2011).

Conducting any type of research in prison is not an easy task. Conducting research with inmates with diabetes has its own set of challenges. Some of the personal and prison related factors and constraints affecting a person's ability to self-care manage diabetes can influence the conduct of research as well. For example, balancing safety with security and accounting for language and cultural differences can affect both the conduct of research as well as an inmate's ability to self-care manage his diabetes.

Having a greater understanding of the factors that affect glycemic control in the incarcerated population and the challenges that can impact the conduct of rigorous research in this area is needed to improve diabetes outcomes and reduce or prevent morbidity and mortality with this vulnerable population. And because diabetes requires a high degree of self-care management and inmates have unique and varied constraints to self-care, an exploration of factors affecting self-care for diabetes is needed for the purpose of informing future practice and research with incarcerated persons.

## **Purpose**

The primary purpose of this dissertation is to lay the foundation for developing interventions to improve diabetes self-care management and glycemic control in incarcerated person with diabetes. To achieve this purpose, three papers are presented. The aims of the three papers presented in this dissertation are to:

1. Examine relationships of illness representation, diabetes knowledge, and self-care behaviors with respect to glycemic control in incarcerated persons with diabetes.
2. Identify, and discuss the methodological challenges for conducting clinical behavioral diabetes research in the correctional setting and with incarcerated persons and to propose modifications for minimizing these challenges.
3. Examine self-care for diabetes in the incarcerated population within the framework of the Rediscovery of Self-Care (RSC), a newly developed care model for persons with incarceration experience.

## **CHAPTER II**

Article one: Relationships of Illness Representation, Diabetes Knowledge, and Self-care  
Behavior to Glycemic Control in Incarcerated Persons with Diabetes

Author Note: Intended for submission to *Research in Nursing & Health*

## Abstract

Illness Representation, diverse health beliefs, constrained self-care behavior, cognitive vulnerabilities and knowledge deficits are key issues for incarcerated persons with diabetes. A cross sectional design was used to examine relationships of diabetes knowledge, illness representation and self-care behaviors with respect to glycemic control in 124 incarcerated persons who completed surveys related to diabetes knowledge, illness representation, and self-care behavior. Self-care behavior, Illness Representation and diabetes knowledge were measured using the SCI-R (Self-care Inventory Revised), and SKILLD (Spoken Knowledge for Low Literacy in Diabetes) and BIPQ (Brief Illness Perception Questionnaire) instruments respectively. The ability of summary scores and items from these instruments to predict glycemic control (A1C) was evaluated using linear regression analyses. The final regression model was statistically significant ( $F_{(1, 24)} = 9.51, p < 0.001, R^2 = 19.2\%$ ). Higher log10 HbA1C (A1C) was associated with lower personal control beliefs ( $B = -0.007, t = -2.42, p < 0.05$ ), higher self-report of diabetes understanding ( $B = 0.009, t = 3.12, p < 0.05$ ) and being on insulin ( $B = 0.06, t = 2.45, p < 0.05$ ). Metabolic control was suboptimal for diabetic inmates.

## **Background**

Research in the correctional setting or with incarcerated persons with diabetes is essentially nonexistent. Yet among 244,336 jail and 49,702 Federal, and 524,116 state prison inmates, there was an age adjusted diabetes prevalence of 11.6%, 10.1% and 8.1% respectively as compared to 6.5% diabetes prevalence among non-institutionalized members of the general population (Wilper et al., 2009). Inmates are disproportionately from ethnic minorities and carry a greater burden of chronic illnesses such as diabetes when compared to non-Hispanic white persons. Furthermore, with the aging prison population and the increased incidence of obesity and diabetes in community dwelling adolescents and young adults, diabetes prevalence in the prison setting is predicted to rise (Lorber et al., 2013). With these predictions, correctional health care can anticipate that there will be many more inmates with Type 1(T1DM) and Type 2 (T2DM) diabetes and similar to community dwelling individuals these inmates will likely have medical expenditures 2.3 times greater than inmates without a diagnosis of diabetes (ADA, 2013).

In non-pregnant adults, lowering or maintaining the A1C level below or at 7% has been shown to decrease diabetes related micro and macrovascular complications (ADA, 2014). Engaging in self-care behavior (SCB) for diabetes is integral to achieving good glycemic control and reducing the incidence of complications (American Association of Diabetes Educators [AADE], 2014; ADA, 2014a; Haas et al, 2013). Theoretically, this should be no different for incarcerated persons with diabetes.

Other factors identified as contributing to better glycemic control in community dwelling persons with diabetes include: having better knowledge about diabetes (Berikai et al., 2007; Hartz, Kent, James, Xu, Kelly, & Daly, 2006; Panja, Starr, & Colleran, 2005 ), regular

performance of self-care (Chiu & Wray, 2010; Glazier, Bajcar, Kennie, & Wilson, 2006; Jones et al., 2003; Murata et al., 2009; Norris, Lau, Smith, Schmidt & Engelgau, 2002; St. John, Davis, Price, & Davis, 2010 ), higher self-efficacy (Bean, Cundy, & Petrie, 2007; Gao et al., 2013); Krichbaum, Aarestad, & Buethe, 2003), favorable illness representations or one's perceptions about diabetes (Bean, Cundy, & Petrie, 2007; Hagger & Orbell, 2003; Keogh et al., 2007, 2011; McSharry, Moss-Morris & Kendrick, 2011), and greater adherence to medication (Bains & Edege, 2011; Lawrence, Ragucci, Long, Parris, & Helfer, 2006; Rhee et al., 2005). Other factors found to adversely affect glycemic control include low health literacy (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Schillinger et al, 2002; Tang, Pang, Chan, Yeung, & Yeung, 2008) and depression (Lustman et al., 2000).

To improve diabetes education, care and outcomes, researchers are integrating the aforementioned factors into comprehensive clinical trials and interventions for community dwelling adults with diabetes. There is already a great deal of evidence that supports a variety of interventions for improving diabetes outcomes in the community (ADA, 2014).

Notably, none of this evidence has been translated to the correctional setting. Because of this, our understanding and explanation of factors contributing to glycemic control in the prison is inferior to what we know about diabetes and glycemic control among members of the general population. Essentially, we have little research from which to build evidence based diabetes care in the prison.

Preliminary work from a quality improvement initiative involving a prison adapted Group Medical Appointment (GMA) conducted by a Department of Corrections [DOC] (Gallagher, LaFrance, & Neff, 2011) in northeastern United States suggested that some inmates had negative health beliefs or illness perceptions and limited diabetes knowledge even after

participating in the program for over a year (Reagan, 2011). Innovative and sophisticated self-care practices were described by a few inmates who attended the GMA feedback sessions (Reagan, 2011). All thirteen participants touched on at least one example of each of the AADE's 7 (AADE7) SCBs (AADE, 2014; Haas et al., 2013). Engaging in SCB for diabetes is integral to achieving good glycemic control and reducing the incidence of diabetes related complications (AADE, 2014; ADA, 2014; Haas et al., 2013).

Consequently, this feedback from inmates with diabetes along with the belief that cognitive, emotional, cultural and behavioral (addiction) components are widely present among inmates or perhaps distinctively different from those persons with diabetes living in the general population provided background information for the development of this study. The purpose of this exploratory study was to examine the relationships of diabetes knowledge, illness representation and SCB with diabetes with respect to glycemic control in incarcerated persons with diabetes.

### **Theoretical Framework**

Illness representation is formed from the individual's beliefs, perceptions and available skills for management of the health threat (Leventhal, Diefenbach, & Leventhal, 1992; Leventhal, Leventhal & Contrada, 1998; Leventhal, Safer, & Panagis, 1983). Cognitive and emotional dimensions of illness representation include: identity or how the person labels the health threat, timeline or acute/chronic nature of the threat, consequences of health threat (outcome or complications of illness), the cause or etiology of the health threat and the cure or control of the health threat (Leventhal et al., 1983). In subsequent research, Moss-Morris et al. (2002) identified emotional representation, concern, and coherence/comprehension of illness as additional components of illness representation.



The Common Sense Model of Illness (CSMI) has been used with increasing frequency to describe and explore the process of self-regulation of health and illness for community dwelling persons with diabetes and other chronic illnesses (Gherman et al., 2011; Leventhal, Weinman, Leventhal & Phillips (2008); McSharry, Moss-Morris & Kendrick, 2011). The CSMI serves as a framework for exploratory descriptive and more recently intervention research surrounding the construct of illness representations or a person's common sense beliefs about illness (Leventhal et al., 1998; Leventhal et al., 1983; McAndrew, Horowitz, Lancaster, & Leventhal, 2010). According to Leventhal et al. (1992) and Leventhal et al. (1998) illness representations or perceptions of illness are framed by the person's past, his beliefs about what he thinks caused the illness, the timeline or course (how long it will last), and consequences of the illness (Harvey & Lawson, 2008). And one's illness representations also take into account if the illness is curable or controllable.

For the current study, the CSMI provides a framework to explore, describe and understand ethnically diverse inmates' beliefs and perceptions of diabetes and their relation to glycemic control. Additionally, the conceptual model for this study was derived from empirical knowledge of the realized benefits of self-care behavior on glycemic control (AADE, 2014; Beverly et al., 2013; Gao et al., 2013; Sousa & Zauszniewski, 2005).

## **Method**

### **Design**

A cross sectional design was used to examine factors related to glycemic control among incarcerated persons with diabetes. Interviews with inmates were conducted to collect data on knowledge, illness representation, and self-care for diabetes.

## **Sample and Recruitment**

Procedures for the identification of inmates with diabetes were determined in collaboration with the DOC of the study site. The researcher committed to being available for blocks of time on predetermined dates to meet with inmates who were interested in volunteering to participate in this study. Once they agreed to participate and were consented, inmates were interviewed by the researcher.

After a thorough search of the literature and consultation with a statistician, it was determined that there was not similar prior research from which to estimate an effect size. Alternatively a power analysis was performed with the Power Analysis and Sample Size (PASS) software program (NCSS , LLC Kaysville, Utah) using correlation coefficients from earlier research with the Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006). That research showed correlation coefficients of .28-.44. A sample of 123 participants would be necessary to detect Pearson correlations with magnitude of .25 or greater, a power of .80 and alpha .05 (two tailed).

All persons with T1DM or T2DM of any gender, race or ethnicity who were incarcerated in selected prisons in Northeast were eligible to participate if s/he was: able to speak and understand English; able to read English or Spanish; age 18 or older; housed in a general facility population; had the capacity to agree to voluntarily participate and to provide written consent. Exclusion criteria included inmate patients who did not have an A1C result in the CMHC database within a year of the date of the interview. All 125 participants enrolled in this study had an A1C assessment performed less than eight months from the date of the interview.

Inmates were recruited from five DOC medium to high security facilities in Northeastern United States. Potential participants were screened and if screening criteria were met invited to

participate in this study. Recruitment flyers, available in English and Spanish at a fifth grade reading level, were posted in the medical and housing units and available during the insulin administration line at each of the participating facilities. Additionally, the researcher was available at predetermined times in conjunction with routine care to provide additional information or answer additional questions. Inmates who were interested in participating in the study wrote on a medical request slip his/her name and the words “Diabetes Study” and placed the medical request slip in the medical appointment box. Medical request slips for the “Diabetes Study” were sorted by a DOC nurse and given to the researcher.

## **Procedures**

Institutional Review Board (IRB) approval was obtained from the University of Connecticut and the Research Advisory Council (RAC) of the department of corrections. A National Institute of Health (NIH) Certificate of Confidentiality (COC) was obtained to protect the privacy and confidentiality of the study participants. The researcher, worked with the DOC administration, Correctional Officers (CO) and nursing staff to facilitate access into each facility, arrange transport of the participant to and from the researcher, identify a private yet secure space to screen, consent and enroll participants.

If eligible and after consent, participants met with the researcher for one-on-one interview lasting less than one hour. Data were collected from two primary sources: 1) one-on-one interviews with inmates, and 2) DOC electronic databases for retrieval of A1C. With the exception of the REALM and SAHLSA, all instrument items were verbally administered in English. Responses to items and questions were recorded verbatim on each instrument. Participants provided self-report data on demographics (age, gender, ethnicity), health status (type of diabetes, duration of illness and/or age at diagnosis), medications including dose, type,

frequency, and administration method (keep on person[KOP], or direct observation medication line), medical problems including whether T1DM and T2DM, mental illness and prior alcohol/substance abuse, and years in prison. Forms were coded and the self-report demographic history and consent form were filed in a secure file separate from the deidentified data. No participant required a rest break and all completed the study in less than one hour. At the end of interview, participants received a certificate of participation.

## **Measures**

**Covariate health literacy.** Participants who read English were screened for health literacy with the Rapid Estimate of Adult literacy in Medicine (REALM) (Davis et al., 1993). If the inmate read-Spanish only, the Short Assessment of Health Literacy for Spanish Adults (SAHLSA-50) (Lee, Bender, Ruiz & Cho, 2007) was used to assess health literacy, and a certified Spanish translator was made available for the health literacy screening.

The Rapid Estimates of Adult Literacy in Medicine (REALM) (Davis et al., 1993) is a 66 item instrument used to estimate the literacy level of English speaking adults. Scores range from 0-66 and are classified as 3<sup>rd</sup> grade and below (0-18), 4<sup>th</sup> to 6<sup>th</sup> grade (19-44), 7<sup>th</sup>-8<sup>th</sup> grade (45-60), and high school (61-66) reading level. Davis et al. reported that persons scoring 61 or greater will be able to read most patient education materials and will not be offended by low literacy materials. The REALM has been widely correlated with several other standardized reading tests including the Wide Range Achievement Test (WRAT) ( $r=0.88$ ), Peabody Individual Achievement test (PIAT-R) ( $r=0.97$ ) and the Slosson Oral Reading Test Revised (SORT-R) ( $r=0.96$ ). The REALM has a test-retest ( $n=100$ ) reliability coefficient of 0.99 (Davis et al., 1993; DeWalt et al., 2004).

The Short-Assessment of Health Literacy for Spanish Speaking Adults (SAHLSA-50) is a 50 item instrument designed to test reading recognition and comprehension of common medical terms in Spanish speaking adults (Lee et al., 2007). Scores range from 0-50 with a cutoff point of 37 points or less indicating inadequate health literacy. The SAHLSA-50 has good internal reliability (Cronbach's alpha 0.92) and good test-retest reliability (Pearson's  $r=0.86$ ) (Lee et al., 2007).

For the current study, participants were dichotomized as having adequate health literacy or inadequate health literacy. Those with a REALM score of 61 or greater i.e. having health literacy skills described as being able to read most patient education materials and not being offended by low literacy materials, or scoring 38 or higher on the SAHLSA were categorized as having adequate health literacy.

**Dependent variable: glycemic control.** The hemoglobin A1C was used as a measurement of glycemic control and was extracted from a DOC electronic database. Retrieved A1Cs were performed less than 8 months from the date of the interview. The A1C performed on the date closest to the inmates' research participation was entered into the regression analysis.

**Independent variables.** For this study, we found no suitable instruments related to illness representation, SCB, or diabetes knowledge that have been evaluated specifically within the incarcerated population. The instruments were selected because they were developed for community dwelling populations with characteristics or behaviors comparable to those of many incarcerated persons.

**Self-care behavior.** The Self-care Inventory- Revised (SCI-R), a fifteen item five point Likert scale, provides an estimate of the degree to which the participant thinks that s/he follows diabetes treatment recommendations (LaGreca, 2004; Weinger, Butler, Welch & LaGreca,

2005). High scores indicate a greater level of self-care. Weinger et al. (2005) report that three of the items including checking ketones when glucose is high, wearing a medic alert bracelet and adjusting insulin based on food, exercise and glucose values are not scored if the person completing the instrument has T2DM. SCI-R is a one factor scale with high internal consistency ( $\alpha=0.87$ ). For the current study, the three items usually scored for persons with T1DM were not used at all because they were not applicable or allowable to the incarcerated population. An additional item, treat blood glucose with just the recommended amount of carbohydrate, was deleted because it was not applicable to the incarcerated population. The resulting scale included twelve items reflecting SCBs performed within the prison in some capacity.

***Illness representation.*** The Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006) is a 9 item Likert scale which measures nine domains of illness representation including timeline, consequences, identity, personal control over illness, treatment control, emotional responses, and concern and illness coherence/understanding. The BIPQ is much shorter than the more extensive Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996; Moss-Morris et al., 2002), and was selected to reduce participant burden. The BIPQ can be interpreted as a single item summary score with high scores indicating a more threatening view of diabetes (Broadbent et al., 2006). Cronbach's alpha for the BIPQ summary score have been reported at 0.58-0.70 (Bean et al., 2007). The BIPQ has good concurrent, predictive and discriminate validity (Broadbent et al., 2006).

***Diabetes knowledge.*** Spoken Knowledge in Low Literacy for Diabetes scale (SKILLD) (Rothman et al., 2005) is a 10 item scale that measures diabetes knowledge. Scores range from 0-100 with higher scores indicating greater diabetes knowledge. Cronbach's alphas for the SKILLD have been reported at 0.72 (Rothman et al., 2005) and 0.54 (Jeppesen et al., 2011).

Both Rothman et al. and Jeppesen's et al. studies supported construct validity and moderate criterion validity with the SKILLD. Despite the low Cronbach's alpha in the later study, an expert in correctional healthcare determined that the SKILLD had face validity for use with the proposed study population.

### **Statistical Methods**

Data were analyzed using the SPSS 18.0 statistical package (SPSS, Armonk, New York). Univariate statistics were used to describe the sample. All data were examined for accuracy of data entry, missing values, and fit between their distributions and the assumptions of multivariate analysis. The ninth item of the BIPQ, a write-in reflecting a person's causal etiology of diabetes, was not analyzed. The SCI-R, BIPQ and the SKILLD instrument summary score had Cronbach's alphas of 0.57, 0.60, and 0.65 respectively. Because the Cronbach's alpha for all instruments did not reach the level for strong internal consistency and both the SCI-R and BIPQ summary scores were not related to glycemic control, individual instrument item scores were examined in linear and multivariate regression models. For this process, a hybrid backward and forward variable selection strategy that identified significant correlates of A1C and controlled for potential confounding by covariates was used to identify a parsimonious multivariable model. Logarithmic transformation (base 10) of A1C accounted for heteroscedasticity in its variance.

### **Results**

#### **Socio-demographics**

Of the 125 persons who participated in this study, 124 were included in the analyses. One participant responded "I don't know" to several of the BIPQ and SCI-R items. As a result he was missing essential data for the regression model. The sample was predominantly male, black or non-Hispanic white, with high school education or less with poorly controlled

T2DM (Table 1). Over half of the participants on screening had inadequate health literacy as determined by the REALM and SAHLSA and the majority had a HS diploma or GED. Sixty-five percent had a history of alcohol or substance abuse. On average, the participants were relatively young when diagnosed; the majority were on insulin and had diabetes for over six years.

### **Instrument Summary Scores and Item Analysis**

Table 2 provides instrument summary and item scores. The three SCBs performed with the least frequency by incarcerated persons included recording blood glucose results, keeping food records and carrying quick acting sugar to treat low blood glucose. Responses to the SCI-R indicated that the incarcerated participants in this study rarely or never recorded their blood sugars or kept food records. Participants' belief that they could control their diabetes was ranked lowest from the BIPQ. Their concern for diabetes ranked highest from the BIPQ.

Scores for diabetes knowledge (SKILLD) were above average at 67.7 % ( $\pm 18.75$ ). When compared to scores on other diabetes related knowledge items, most of the participants had less understanding of the exercise requirements for diabetes, the meaning of the A1C, and the range for the normal fasting blood sugar.

The SKILLD summary score, accounting for 6% of the variance in Log 10 A1C (LogA1C), was the only instrument summary score with a significant positive relationship ( $p < 0.05$ ) to LogA1C (Table 3). Because of this and in order to identify the best fitting multivariate regression model, simple linear regression analyses as described under statistical methods section of this paper were performed using the instrument items.

### **Simple Linear Regression Models**



Significant results of the simple linear regression models with covariates and independent variables are displayed in Table 4. Lower LogA1C was associated with only one SCB- eating the correct food portions ( $B=-0.015$ ,  $t=-2.29$ ,  $p<0.05$ ). On the BIPQ, higher LogA1C was associated with self report of experiencing greater diabetes related symptoms ( $B=0.007$ ,  $t=2.25$ ,  $p<0.05$ ), greater understanding of diabetes ( $B=0.010$ ,  $t=3.31$ ,  $p<0.05$ ) and a longer timeline or a belief that diabetes will be chronic in nature ( $B=0.007$ ,  $t=2.25$ ,  $p<0.05$ ). Only one item on the SKILLD, knowing the normal value for A1C, was predictive of LOGA1C and accounted for 5.5% of the variability in LogGA1C. Participants having greater understanding of the normal value of A1C had higher LogA1C ( $B=0.049$ ,  $t=2.66$ ,  $p>0.05$ ).

Being on insulin ( $B=0.091$ ,  $t=3.60$ ,  $p<0.001$ ) and having diabetes for five years or less ( $B=-0.049$ ,  $t=-2.51$ ,  $p<0.05$ ) were the only covariates contributing significantly to LOGA1C in simple linear regression.

### **Multivariate Models**

In the next step, a best-fitting multiple regression model was developed based on significant independent variables from the bivariate analyses that included SCI-R Eat the correct food portions, BIPQ Timeline, Personal control, Identity, and Coherence and SKILLD Know the normal A1C value. Through this process, two independent variables, personal control beliefs and coherence (self report of diabetes understanding), were retained in the resulting model ( $F(2,124)=10.81$ ,  $p<0.05$ ,  $R^2=15.2\%$ ) (Table 5). Higher LogA1C was associated with lower personal control beliefs and higher self report of diabetes understanding. This finding was consistent with what was found in the simple linear regression models performed with these variables.

For the last step, covariates were entered and removed from the independent variable model. Being on insulin was the only covariate retained in the final multiple regression model. The final regression model predicting LogA1C included being on insulin, personal control beliefs and self report of diabetes understanding (Table 6). The final regression model was statistically significant ( $F(3,124) = 9.51, p < 0.001, R^2 = 19.2\%$ ) (Table 6). Higher log10A1C was associated with lower personal control beliefs ( $B = -0.007, t = -2.42, p < 0.05$ ), higher self-report of diabetes understanding ( $B = 0.009, t = 3.12, p < 0.05$ ) and being on insulin ( $B = 0.06, t = 2.45, p < 0.05$ ).

## **Discussion**

The main findings of this study indicated that inmates having poorer glycemic control and on insulin, having greater perceived understanding and lower personal control beliefs were independent predictors of higher A1C. This was true regardless of age, ethnicity, duration of diabetes and incarceration, performance of self-care behaviors, number of chronic illnesses or number of medications. These findings as well as the insignificant findings provide insight and understanding into factors that can influence glycemic control in the correctional setting.

### **Glycemic Control**

Recommended A1C goals were not met for these participants. The ADA (2014) acknowledges that an A1C of less than 8% rather than 7% may be acceptable for patients with a history of severe hypoglycemia, extensive comorbid conditions and patients with long-standing diabetes and difficulty achieving control. We did not examine incidence of hypoglycemia as a variable. The ADA (2014a) also states that an A1C of 6.5% may be required for someone with longer life expectancy or earlier in the disease process. Whether this was the case for the participants of this study is not known. Intensive blood glucose control has been associated with

an increased incidence of hypoglycemia (ADA, 2014; UK Prospective Diabetes Study [UKPDS] Group, 1998). The ADA (2014b) reported that in 2011, 282,000 patient visits to the emergency department had hypoglycemia listed as the first diagnosis. Incarcerated persons were not separately identified in these numbers. On the other hand, the complications of poorly controlled diabetes and hyperglycemia are well documented (Epidemiology of Diabetes Interventions and Complications [EDIC], 1999; The Diabetes Control and Complications Trial Research Group [DCCT], 1993).

Participants in this study did not have access to a glucometer. Therefore, they were not able to validate signs and symptoms of hyper- and hypoglycemia by checking a blood glucose unless they went to the medical clinic. The reasons for poor glycemic control among participants in this study are unknown and are likely multifactorial. Further research should be conducted with the incarcerated population to examine relationships among glycemic control, demographic and clinical factors e.g. severity of illness, the incidence of hypoglycemia and hyperglycemia, and number of emergency room visits. Data from national and international correctional settings should be disseminated with regard to successful pilot studies or quality improvement initiatives related to safe use of a glucometer by inmates.

### **Instrument Summary Scores**

The SKILLD instrument had the highest reliability of all the study instruments and was the only instrument summary score to have a significant albeit positive association with glycemic control. The SKILLD was designed and tested in a community based low literacy population (Rothman et al., 2005) so perhaps this was the best suited instrument of the three for this population. However, the SKILLD summary score was not significant in the final regression model.

The BIPQ has been used most often in community dwelling persons with diabetes as a scale with nine separate domains rather than a summary score. The low reliability of the BIPQ summary score with this population and inconsistent reliability (0.54-0.72) in community dwelling participants suggest that using the nine item BIPQ scale modeled after the longer Illness Representation scale is a better option to explore and understand relationships among variables.

The SCI-R was not significantly related to glycemic control. However with not having a strong level of internal consistency, the lack of significance for this instrument must be interpreted with caution. Other factors such as the structured highly controlled prison environment and strict rules may have played a role in the low internal consistency for the data associated with this measure of self-care. For example, inmates on insulin are required to check their blood glucose daily or potentially risk receiving a disciplinary ticket for committing an infraction of the rules. Prison rules such as these likely influenced SCI-R responses pertaining to the frequency of checking blood sugars. An in-depth analysis of data associated with all of the instruments and further testing and revision of other instruments is needed.

### **Illness Representation**

Several domains of Illness Representation were significant in the linear regression models but only personal control beliefs and self report of diabetes understanding remained significant in the final regression model. In this study, personal control beliefs had an inverse relationship with glycemic control. With higher personal control beliefs, the better the glycemic control. These findings are consistent with what is reported in the CSMI literature (Broadbent, 2006; Broadbent, Donkin, & Stroh, 2011; Schuez, Wurm, Warner, & Ziegelmann, 2012) and in two prior metaanalysis with non-incarcerated populations (Hager & Orbell, 2003; McSharry,

Moss-Morris & Kendrick, 2011). The implications of this finding for the incarcerated population are great.

Oftentimes cited in the mental health and offender literature, incarcerated persons have numerous cognitive vulnerabilities, maladaptive coping (Bonner, 1992; Bozworth, 2007; Haney, 2006; Shelton, 2009, 2010a) and poor problem solving skills (Eidhin, Sheehy, O'Sullivan, & McLeavey, 2002; Ivanoff, Smyth, Grochowski, Jang, & Klein, 1992). Furthermore, incarceration places significant constraints on individual liberties and places inmates in a dependent role. These characteristics and conditions can affect the ability to effectively self manage (Shelton, 2011).

According to the CSMI, believing that an illness, in this case diabetes, can be controlled leads to the development of adaptive self-management strategies (Breland, McAndrew, Burns, Leventhal, & Leventhal, 2013). Hagger and Orbell's (2003) metaanalytic review of the CSMI for numerous chronic illnesses and conditions found that perceived controllability of illness was associated with cognitive reappraisal, expressing emotions and problem focused coping strategies. In the current study, inmate participants who perceived that diabetes was controllable had lower A1Cs. For future research, it would be important to investigate what sets these inmates apart from their peers who have lower personal control beliefs and worse glycemic control. Inmates who are able to make cognitive reappraisals and problem solve issues related to their diabetes could serve as role models to those inmates who have not developed this capacity.

Although personal control beliefs held as a component of one's CSMI and self-efficacy are different constructs, their relationship bears mentioning. Personal control beliefs as a component of a person's illness representation have been associated with increased self-efficacy in community dwelling adults (Broadbent et al., 2006; Schuez et al., 2012). Schuez et al. found

that older adults with greater self-efficacy were more likely to perceive their multiple illnesses being under their control. If self-efficacy is found to enhance personal control beliefs for inmates with diabetes, intervention development could include multiple targets and potentially result in greater improvements in A1C. Considering the positive relationship between self-efficacy and personal control beliefs and the finding from this study, using evidence based strategies to increase self-efficacy may result in increased personal control beliefs and improved glycemic control. These relationships should be explored and findings can be incorporated into interventions for inmates with diabetes.

Higher self-report of diabetes understanding (BIPQ Coherence) was associated with higher A1C. This is not typical of what's reported in the literature. Research has shown illness understanding or coherence to have no relationship (McSharry et al., 2011) or an inverse relationship to glycemic control (Keough et al., 2011). However, in this study inmates who believed that they understood their diabetes had higher A1C. Incarcerated participants might have overestimated their understanding of diabetes. Overestimating their skills can occur among incarcerated persons who have multiple cognitive vulnerabilities (Sedikides, Meek, Alicke, & Taylor, 2014). Highly structured environments with limited options for self-care, personal choices and readily available health care may give some inmates no motivation to improve diabetes control even if they have an understanding of what to do (Shelton, 2010).

Additionally, professional nursing and medical staff might focus their efforts on those inmates with poorly controlled disease and more diabetes related complications. This might explain the finding that inmates who knew the normal value of A1C had higher A1Cs; these patients might receive more intensive education because of the severity of their illness. Or maybe the inmates with higher A1C become complacent or tired of managing their diabetes.

Complacency has been reported to occur in community dwelling persons who are asymptomatic and has been associated with worse glycemic control (Savoca, Miller, & Quandt, 2004). Inmates with longer sentences or those who are asymptomatic could demonstrate low motivation or complacency. For the inmates in this study, having diabetes for greater than five years was associated with higher A1C but duration of illness was not predictive of A1C in the final model.

### **Diabetes Knowledge**

In linear and multiple regression models, having objective knowledge about diabetes (SKILLD) was not predictive of LOGA1C in the final model. Although not consistently, diabetes knowledge has been associated with better glycemic control in community dwelling populations (Berikai et al., 2007; Fenwick, Xie, Rees, Finger, & Lamoureux, 2011; Hartz et al., 2006; McPherson et al., 2007). The overall diabetes knowledge scores (SKILLD) were above average but certain content areas had much lower scores than other content areas.

For example, inmates had a poor understanding of the acceptable values for A1C and normal fasting blood sugar. Monitoring the A1C and fasting blood glucose is a common and important self-management behavior (AADE 2014; ADA, 2014). It is interesting that most participants reported checking their blood glucose with a monitor “usually” or “always” but the average score for knowing the optimal fasting blood glucose and A1C values were only 29 and 46 percent out of 100 percent respectively. These findings would suggest that many of the inmates are checking their blood glucose often but do not understand what is the normal value.

Current literature indicates that the quality of blood glucose monitoring - knowing how to interpret and what to do with the value- is more important than the frequency or quantity of blood glucose monitoring (ADA, 2014; Breland et al., 2013). Because most inmates in state correctional facilities do not have access to a glucometer, it is essential that they have the

knowledge to interpret the blood glucose when it is checked. Additionally, a key aspect of diabetes self-management is being able to set goals. It is common for person with diabetes to set goals for achieving certain range of blood glucose or A1C (AADE, 2014). For the participants in this study, not having access to a glucometer and not understanding the normal range and value for blood glucose and A1C would make it impossible for them to set and achieve goals.

This study did not examine the relationship between self report of diabetes understanding (BIPQ Coherence) and actual diabetes knowledge (SKILLD). However given the findings of higher A1Cs associated with both perceived understanding (BIPQ coherence) and actual understanding (SKILLD), further examination of these associations is needed. It will be important to determine if incarcerated persons who believe that they understand their illness have actual knowledge about diabetes. Unlike the findings from this research, diabetes knowledge has been associated with better glycemic control in low literacy populations (Bains & Egede, 2011).

Lastly, health literacy, a construct often associated with knowledge, was adequate in half of the study population. Health literacy has been linked to glycemic control but has also been found to exert its effect through knowledge which then affects glycemic control (Bains & Egede, 2011). These questions were not answered by this study but certainly will need to be considered in the future.

### **Insulin Therapy**

The majority of study participants were on insulin. Due to the progressive nature of diabetes, insulin treatment is often required to achieve control at some point in the illness trajectory (ADA, 2014). The purpose of initiating or adding insulin to a patient's regimen is to improve control and reduce or prevent diabetes complications (ADA, 2014; Mosenson & Raz, 2013). Recommended A1C goals of less than 6.5 or 7 percent were not met by this population.



Furthermore, inmates on insulin had higher A1Cs than those inmates not on insulin. Because of the DOC regulations, participants in this study did not self administer insulin and were on a variety of regimens. Further examination of insulin regimens for incarcerated persons and the relationship of individual characteristics e.g. disease severity, type of treatment, frequency of hyper- and hypoglycemia to glycemic control is needed to better understand why inmates on insulin had higher A1Cs.

### **Self-care Behavior**

Eating the correct food portions was associated with lower A1C in linear regression models but not in the final multiple regression model. This was the only significant finding related to a diabetes self-care behavior. In preliminary work with this population (Reagan, 2011), inmates reported using self-care strategies for modifying food selection and portion size. Typically, they described bartering unhealthy choices or high carbohydrate foods for fruit or cutting their portions in half. Although inmates have for the most part predetermined food selections, they can make healthier choices from the prison commissary if they have the money and desire to do so. Given this finding, interventions targeting the commissary behaviors are warranted.

Keeping a record of blood glucose values and food intake were two of the most infrequently performed self-care behaviors. When asked the question about recording blood sugars, participants in this study often commented, “The nurse keeps track of my blood sugar results”. At all sites participating in this study, the health clinic staff maintained the record of the inmate patient’s blood sugars. This process does not motivate the inmate to take control of this self-care behavior. Self monitoring of blood glucose (SMBG) is one of the AADE7 SCBs

(2014). Engaging the inmate in this process would facilitate problem solving- another AADE7 SCB. These skills would be of value to the inmate upon release into the community.

Concern for the safety and security of staff and other inmates' do factor into the decision to allow inmates to keep a glucometer on person. There has been no research to examine the feasibility and safety of allowing inmates to have access to a glucometer. However, a pilot quality improvement project is under way in some states to evaluate the effect of having KOP glucometers for inmates with diabetes (Ball, 2011). Preliminary findings for this quality improvement study support having a KOP glucometer for selected inmates. Preliminary findings indicate that inmates using the glucometer have increased self-care in this area and have improved health outcomes (Ball, 2011)

### **Health Disparities**

National statistics on racial and ethnic composition of incarcerated persons approximated the racial and ethnic composition of this study (Bureau of Justice, 2013). For the current study, white participants approached 40% of the sample and the African-American population was close to 50% slightly higher than the 38% reported by the BJS for nationwide incarceration of black inmates in 2011. Incarcerated females were underrepresented in this study. Although, there are less incarcerated females than males, female prisoners are thought to be especially vulnerable to the effects of incarceration.

Additionally, monolingual Spanish speaking Latino inmates were not included in this study. Efforts should be made to reach all ethnic groups and to obtain funding for certified translators to assist with recruitment of non-English speaking inmates. It is critical to have adequate representation of Latino persons for any diabetes related research because they have a high prevalence of diabetes (ADA, 2014). Engaging females and racial and ethnic minorities in

research and self-care can help us to better understand how to treat this chronic illness and help inmates to improve their health while in prison. By improving health and decreasing morbidity associated with diabetes, these measures can potentially increase the health of the community to which they are released.

### **Limitations**

Because a cross sectional design was used for this study, the ability to generalize findings and infer causality is limited. Secondly, with the limited number of female participants generalizability is more limited for this subpopulation. However, limitations are outweighed in that this is the only study found reporting on inmates' illness representations, diabetes knowledge and self-care behaviors. The findings from this research will serve as a foundation for the development of evidence based and cost effective interventions for diabetes management within the correctional setting.

Additionally, all measures but the A1C were self report. Self report by inmates might be influenced by prison culture and therefore be less than truthful. Incarcerated persons often become accustomed to the predatory nature of social and interpersonal relationships within the prison and as a result may become suspicious of others (McKorkle, 1992). These types of social behaviors have been discussed in the literature under the term of prisonization or the psychological effects of incarceration (Adams, 1992; Dobbs & Waid, 2012; Haney, 2006; Schnittker, 2014). Researchers working with this population must be cognizant of these behaviors.

Additionally, there could be as much as a seven month gap between the measurement of A1C and the assessment of the illness representation, SCB, and diabetes knowledge constructs.

This gap is likely to be a source of variability in study measures that may make it more difficult to detect relationships via statistical testing.

Obtaining a NIH COC, as was done in this study, may give incarcerated research participants some reassurance that researchers are taking measures to protect their privacy and confidentiality. Having the COC could decrease the inmates' distrust of the researcher and promote honest self report. Future studies that validate self report data of incarcerated persons to objective data in the medical record would elucidate the extent of this issue. Having access to medical records and other forms of objective data through the process of informed consent is ideal for promoting research rigor and generalizability. However, working with the vulnerable incarcerated population, these data are often restricted by the IRB even before the informed consent process has taken place.

Development of valid and reliable instruments to measure behavioral and conceptual variables such as self-efficacy and self-care is needed. Given the anticipated rise in prevalence of diabetes in this population, identifying effective approaches for improving diabetes outcomes in the prison is imperative. Consideration and reevaluation of prison constraints related to use of glucometer might lead to the development of innovative strategies to improve self-care for this population.

Although important associations were identified, further research with this population is needed to determine if having increased personal control beliefs consistently improves glycemic control along with other self-care behaviors. Further exploration of the association between having higher self reported diabetes knowledge and worse glycemic control and to examine mediating and moderating relationships among self-care, illness representation and the presence of comorbid conditions such as substance abuse and mental illness is needed. Future research

should test interventions to improve self-efficacy or personal control beliefs for incarcerated person with diabetes. More important is examining the effect of these interventions on the health outcomes and well being of incarcerated person upon re-entry into the community. Our results suggest that enhancing diabetes personal control beliefs among inmates may lead to lower A1C. Outcomes of this research will serve as a foundation for developing evidence based interventions for incarcerated persons.

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Table 1

*Sociodemographics and Clinical Characteristics of Incarcerated Persons with Diabetes (N=124)*

Characteristic	N	%	M	SD
Gender				
Male	116	93.5		
Female	8	6.5		
Age			47.32	9.46
Race				
White, non-Hispanic/Latino	42	33.9		
Hispanic/Latino	29	23.4		
Black	53	42.7		
Marital Status				
Single/Divorced/Separated	101	81.5		
Married/Partner	23	18.5		
Education				
< High School/GED	34	27.4		
Length of Incarceration $\leq 5$ years	81	65.3		
Health literacy, Adequate	70	56.5		
Number of Chronic Illnesses			3.45	1.56
Past History Substance or Alcohol	80	64.50		
Total number of Medications				
0-3	33	26.6		
4-6	74	59.7		
>6	17	13.7		
Insulin Therapy	106	85.5		
A1C			8.17	1.96
Diabetes - Types	16	12.9		
Type 1	74	59.7		
Type 2	34	27.4		
Uncertain				
Age At Diagnosis			35.74	12.85
Diabetes Duration $\leq 5$ years	42	33.90		

Table 2.

*SCI, BIPQ, and SKILLD Summary and Item Scores and Instrument reliability (N=124)*

Item		M	SD	% Correct
SCI	Self-care*			
	Summary Score	38.37	6.29	
	Check Blood Glucose With Monitor	4.69	0.84	
	Record Blood Glucose Results	2.25	1.69	
	Take correct dose diabetes pills/insulin at the right time	4.56	0.83	
	Take diabetes pills/insulin at the right time	4.19	1.11	
	Eat recommended food portions	3.31	1.41	
	Eat meals/snacks on time	3.40	1.14	
	Keep food records	1.89	1.58	
	Read food labels	3.50	1.67	
	Carry quick-acting sugar for lows	2.33	1.64	
	Come in for appointments	4.71	1.85	
	Exercise	3.55	1.30	
BIPQ	Illness Representation*			
	Summary Score	45.80	12.35	
	Consequences	7.06	2.91	
	Timeline	7.48	2.92	
	Personal Control	5.64	3.16	
	Treatment Control	7.06	3.28	
	Identity	5.83	3.00	
	Concern	9.16	1.94	
	Coherence/Understanding	7.06	3.12	
SKILLD	Emotional representation	5.97	3.37	
	Knowledge of*			
	Summary Score	67.66	18.75	
	Signs of hyperglycemia			61.30
	Signs of hypoglycemia			60.50
	Treatment of hypoglycemia			91.10
	Frequency of foot care			69.40
	Frequency of eye exams			73.40
	Importance of foot care			74.40
	Normal fasting glucose			29.00

Normal A1C ( $\leq 6.0\%$ or goal $\leq 7.0\%$ )	46.00
Frequency of exercise	16.10
Long-term complications of diabetes	82.30

\*SCI: How well have you followed your prescribed regimen for diabetes care in the past month? Likert scale; 0=Never, 5=Always

BIPQ: What number best corresponds to your views? Likert scale varied anchors.

SKILLD: 0=incorrect; 1=Correct; 0-100%

Table 3

*SCI, BIPQ and SKILLD Summary Scores and Simple Linear Regression Predicting A1C (N=124)*

Independent variables	B	SE	t	p	R <sup>2</sup>	R <sup>2</sup> Adj
SCI	-0.001	0.001	-0.67	0.50	0.00	-0.00
BIPQ	0.001	0.001	1.85	0.07	0.03	0.02
SKILLD	0.013	0.005	2.74	0.01**	0.06	0.05

\* df = 1,124 applies to all linear regressions models.

Table 4

*Simple Linear Regression Models of SCI, BIPQ and SKILLD Items and Covariates Predicting Log (Base 10)A1C (N=124)*

Variables	B	SE	t	R <sup>2</sup>	R <sup>2</sup> Adj	P
SCI: Eat Correct Food Portions	-0.015	0.007	-2.29	0.04	0.03	0.02
BIPQ: Timeline	0.007	0.003	2.25	0.04	0.03	0.03
BIPQ: Personal Control	-0.008	0.003	-2.83	0.06	0.54	0.01
BIPQ: Identity	0.007	0.003	2.21	0.04	0.03	0.03
BIPQ: Coherence	0.010	0.003	3.31	0.08	0.08	0.00
SKILLD Know Normal A1C Value	0.018	0.049	2.66	0.06	0.05	0.01
Insulin Treatment	0.091	0.025	3.60	0.10	0.09	0.00
Diabetes Duration <5 Years	-0.049	0.019	-2.51	0.05	0.04	0.01

\* df = 1,124 applies to all linear regression models.

Table 5

*Multivariate Regression Model of Independent Variables Predicting AIC (N=124)*

Variables	B	SE	t	P	R <sup>2</sup>	R <sup>2</sup> Adj	F*
BIPQ7							
Illness							
Comprehension	0.010	0.003	3.58	0.001			
Coherence							
BIPQ3							
Personal Control	-0.009	0.003	-3.14	0.002			
				0.001	0.152	0.138	10.81

\* df = 3,124

Table 6

*Final Multivariate Regression Model of Covariates and Independent Variables Predicting A1C (N=124)*

Variables	B	SE	t	P	R <sup>2</sup>	R <sup>2</sup> Adj	F*
BIPQ7 Illness Coherence							
Comprehension	0.009	0.003	3.12	0.00			
Insulin Treatment	0.062	0.025	2.45	0.02			
BIPQ3 Personal Control	-0.007	0.003	-2.42	0.02			
				0.001	0.19	0.17	9.51

\* df = 3,124

### **CHAPTER III**

#### **Article 2: Methodological Issues Conducting Research with Incarcerated Persons with Diabetes**

Authors note: Intended for publication to *Journal of Nursing Scholarship*

### **Abstract**

**Purpose:** Methodologic issues specific to conducting research with incarcerated vulnerable populations who have diabetes are discussed.

**Organizing Construct:** Much has been written about the ethical and logistical challenges of conducting research with vulnerable inmate population. However, conducting research with inmates with diabetes is associated with additional issues related to research design, measurement, sampling and recruitment and data collection procedures.

**Method:** A cross-sectional study examining the relationships of diabetes knowledge, illness representation and self-care behaviors with respect to glycemic control in 124 incarcerated persons will be used as a case study example to illustrate issues encountered or identified throughout the research process. Research modifications are provided.

**Findings:** Sampling bias due to gender inequity, recruitment of participants not on insulin, and lack of standardized instruments were challenges for this study. Although the risk of hypoglycemia did not occur, it was identified as an important consideration as a result of facility and inmate specific factors. Effective communication techniques included having a designated contact at the facility, calling ahead prior to each research session, and being considerate of the inmate routines and recreation time. Improved communication to the inmate about why he is being called to a location is needed.



**Conclusions:** Challenges for conducting research with inmates who have diabetes are great but not insurmountable. Having an understanding of what the issues are and making modifications increase the opportunities for conducting rigorous as well as facility and inmate friendly research. More participative action research involving inmates is needed.

**Clinical Relevance:** Diabetes is a significant cause of death and disability. Its prevalence in incarcerated person and around the world is predicted to rise. Evidence based diabetes medical care and self-care management are essential for improving diabetes outcomes.

**Keywords:** Research challenges, Inmates, incarceration, methodologic, diabetes, self-management

## **Background**

Inmates have a high burden of chronic illness frequently having multiple coexisting physical and mental health illnesses (Binswanger et al., 2012; Wang and Green, 2010; Wilper et al., 2009). Improving physical and mental health chronic illnesses can enhance incarcerated persons well being and improve outcomes during incarceration and upon re-entry and reintegration into the community (The PEW Charitable Trusts, 2014). Diabetes is one chronic illness that occurs in the prison population at similar or slightly less prevalence than in the community dwelling population (American Diabetes Association [ADA], 2013; Binswanger, Kreuger, and Steiner, 2009; Wilper et al., 2009). The ADA (2013) reports an estimated cost of diabetes mellitus in the community in 2012 as 245 billion and that persons with diabetes have approximately 2-3 times greater medical expenditure compared to person without diabetes. With the aging prison population, increased diagnosis of diabetes in younger persons, and the current estimated diabetes prevalence of 4.8% among inmates predicted to rise (ADA, 2010), the economic burden of diabetes care in the prison is likely to mirror that of the community dwelling population.

Evidence based strategies that have been tested in the correctional setting are needed to enhance inmate health outcomes and to reduce the burgeoning cost associated with diabetes. Designed to help improve chronic disease health care outcomes, the National Commission on Correctional Health Care (NCCHC) has developed diabetes specific disease management guidelines from nationally accepted guidelines of the American Diabetes Association (ADA,

2010; NCCHC, 2013). However, there is very little research that examines diabetes related health outcomes in this population or inmate characteristics that could affect glycemic control or the development of effective diabetes education programming. This is in stark contrast to the abundant diabetes research with community dwelling adults (Reagan, 2014).

The dearth of research in this area is likely the result of the general ethical and logistic challenges of conducting research with prisoners who are recognized as a vulnerable population. Challenges for conducting research with this population have been identified and discussed in the literature at length (Carr, Amrhein, & Devy, 2011; Cislo & Trestman, 2013; Wakai, Shelton Trestman & Kesten, 2009). Major challenges include ongoing stringent regulations for protection of prisoners and the conflicting agendas of corrections staff and academic researchers. The department of corrections staff focus on custody and security aspects of inmate care while researchers seek to conduct research to improve outcomes and healthcare (Cislo & Trestman, 2013).

In addition to the issues and restrictions previously described, conducting research with inmates who have diabetes presents a different set of challenges for the research design, measurement, sampling and recruitment and data collection procedures. Reagan (2014) identified these challenges for this case example while conducting research to examine the relationships of illness representation, diabetes knowledge and self-care behavior (SCB) with respect to glycemic control in incarcerated persons with diabetes. Modifications aimed at reducing the challenges for conducting research with this vulnerable population are proposed.

### **Overview of the Case Study Example**

Using a cross-sectional design, 124 incarcerated persons with diabetes were surveyed regarding diabetes knowledge, illness representation, and SCB. Measures included the Spoken

Knowledge in Low Literacy in Diabetes Scale [SKILLD] for diabetes knowledge (Rothman et al., 2005), Brief Illness Perception Questionnaire [BIPQ] for illness representation (Broadbent et al., 2006) and the Self-Care Inventory Revised [SCI-R] for SCB (Weigner, Butler, Welsh, & LaGreca, 2005; LaGreca, 2004). The ability of summary scores and items from these instruments to predict glycemic control (A1C) was evaluated using linear regression analyses. Covariates in these analyses included age, gender, education, incarceration length, health literacy, insulin use, and medication count and illness duration. A hybrid backward and forward variable selection strategy was used to identify a parsimonious multivariable model. Logarithmic transformation of A1C accounted for heteroscedasticity.

Participants (12.9% Type 1 Diabetes; 85% on insulin; 93.5% male; 40% black; 37% white; 23% Latino; 77% HS or less; mean age 47.3 years) had a mean A1C of 8.2% (SD  $\pm$  ). The final regression model was statistically significant ( $F_{3, 124} = 9.51, p < 0.001, R^2 = 19.2\%$ ). Higher log10 A1C was associated with lower personal control beliefs ( $B = -0.007, t = -2.42, p < 0.05$ ), higher self-report of diabetes understanding ( $B = 0.009, t = 3.12, p < 0.05$ ) and being on insulin ( $B = 0.06, t = 2.45, p < 0.05$ ). Metabolic control was suboptimal for diabetic inmates in this study.

## **Methodological Issues**

### **Research Design Challenges**

Variations in diabetes related policies from institution to institution and national to international prison systems could make designing randomized control trials (RCTs) with adequate sample size problematic. RCTs are considered the gold standard for evaluating programs (National Institute of Justice [NIJ], 2014) but very few have been conducted in the

criminal justice system (CJS). Currently, the NIJ is offering a challenge for researchers to develop timely and effective RCTs that address relevant questions or problems in the CJS.

In the current study, a cross sectional design was used. The policies for self-care behavior and the use of glucometer in the system studied were the same across all facilities. The care process utilized did not provide inmates with access to a glucometer; they waited in line to check their blood glucose at prescheduled times; and had their insulin administered by correctional nurses. However, some inmates were allowed to keep oral medications in their cell (KOP- keep on person) thus allowing some engagement in the SCB of medication taking. These policies were not problematic for the cross sectional design of the current study. However researchers would need to consider the variation in procedures across inmates if testing an intervention using an experimental or RCT design. For example, the different methods of medication administration might be challenging if conducting a RCT to test the effects of an intervention on medication adherence.

A second design challenge lies in finding comparator groups for use in translational or Patient Centered Outcome research related to self- care management. There are numerous research reviews such as Cochrane and systematic reviews that draw on findings of completed research to compare the effectiveness of varied interventions for self-care management in community dwelling persons with diabetes. However findings from these reviews are not directly transferrable to the closed system environment of the prison. Cislo and Trestman (2013) cite the value of conducting a small study first and working closely with the DOC and other key stakeholders at every step of the way.

Another factor to consider when designing research with this population is the frequent movement or transfer of inmates between facilities of higher or lower security levels or due to re-

entry into the community (Wakai et al., 2009). This factor is relevant to conducting research with any incarcerated individuals not just those with diabetes. Depending on the research, this factor can impact multiple points in the research process. For example in this case example, there were four participants who required the use of an interpreter to administer the Short Assessment of Health Literacy for Spanish Adults [SAHLSA-50] (Lee et al., 2006). The SAHLSA was used to evaluate health literacy for Spanish reading participants. When Spanish reading inmates were enrolled, a certified translator returned to the prison to assist the researcher to administer the SAHLSA. None of the four participants were released from prison system during the study period but two did move from their original location. Frequent communication with the department of corrections administration was necessary to obtain help in locating these four participants.

Additionally as a result of the frequent movement of inmates, studies with longitudinal or repeated measure designs can be difficult in this environment, or at a minimum increase the costs of conducting the research. The issue of frequent movement of inmates can also present challenges for attrition and the length of time to complete the research often taking months to years longer to complete a research study (Cislo & Trestman, 2013; Trestman, 2006a, 2006b). These factors all need to be addressed when designing research protocols and grant submissions.

### **Measurement Challenges**

Most instruments used for conducting diabetes behavioral research in the community have not been tested in the prison. For this study, instruments that had face validity for or characteristics relevant to the incarcerated population were used. However, there were still issues with lower than recommended levels of internal consistency. All survey instruments with the exception of the Rapid Estimate of Adult literacy in Medicine [REALM] (Davis et al., 1993),

a Health Literacy measurement, were verbally administered to the participants because of the anticipated low literacy (Carson & Sabol, 2012). Only the SKILLD, designed for persons with low literacy, has been tested and used in prior research as a verbally administered survey to a community dwelling sample (Rothman et al., 2005).

Self-care behaviors (SCB) were measured for the current study. Although an important construct for diabetes behavioral research (AADE, 2014, 2012), instruments designed to measure SCB in research with community dwelling adults do not translate well for measurement of self-care in the prison. As previously mentioned, all participants in this study being from one correctional system followed uniform policies related to blood glucose monitoring and insulin administration. However, personal inmate factors such as low socioeconomic status influenced whether or not an inmate had the potential to perform certain SCBs included on the Self-Care Inventory Revised Instrument (Weigner et al., 2005).

For example in the current study, one of the SCBs examined was whether or not the inmate was reading food labels. This was rated on a five point likert scale with “0” being never reads food labels and “5” being always reads food labels. In the prison some inmates with the financial means have the opportunity to purchase commissary foods. These inmates may be reading food labels at the commissary. There are no easily available options to read food labels for the foods provided at scheduled mealtimes. Inmates without access to commissary will not have opportunities for reading food labels.

To illustrate this point consider two participants who responded “never” to the SCI-R item asking about frequency of checking food labels. These participants did not have money to purchase foods through the commissary. For the two participants in this study who had no money to purchase commissary food, performing that SCB was not within their power.

Understanding the meaning behind the “never” response is important if the researcher is examining the effect of an intervention on diabetes self-care behavior such as frequency of reading food labels.

Measuring diabetes SCB in prison requires that the researcher have an understanding of factors, even if nonmodifiable, that influence the performance of SCB beyond the effects of an intervention or a participant’s motivation and self-efficacy for self-care. Socioeconomic status, still a disparity in the prison, can be an influencing and constraining factor to the performance of some SCBs (Secrest et al., 2011).

When selecting instruments and variables, personal factors affecting self-care need to be explored, accounted for and modifications made when possible. Research modifications include: reading the instruments to participants and pilot testing of this process; incorporating participatory processes with inmates who will be participating in the study; having knowledge of inmate prison life so that additional questions can be asked, such as- do you have access to the commissary? Or, asking inmates about their job in prison would be important. For example, inmates working in the kitchen or in a community garden may have access to extra meal trays or other nutritional food. These factors may alter nutritional intake and confound results. Controlling methodologically or statistically for these factors will improve research rigor.

These examples illustrate the hidden challenges of conducting research within a closed yet not entirely controlled system. Factors including low health literacy, ethnic diversity, and constraints to self-care behavior all within the realm of possibility in this environment require that instruments be pilot tested and that data from participatory process with inmates e.g. focus groups be used when developing instruments for future research.



## **Recruitment and Sampling Challenges**

In the current study, 85% of the participants surveyed were on insulin. Depending on procedures for medication administration, recruiting inmates with Type 2 diabetes (T2DM) not on insulin might be challenging. Inmates on insulin came to a medication line to check their blood glucose and receive their insulin once or twice a day; whereas inmates not on insulin could have keep on person (KOP) medications in their cell. Those inmates not on insulin might come to the medication line once a day to check their blood sugar or might not have it checked at all. This may have been one of the reasons for the low number of participants in this study who were not on insulin. Further exploration of the reasons for a low number of participants in this study who were not on insulin is needed. Research modifications include: arrange for in person information session about the study at varied times and locations; if identification of inmates not on insulin is possible via an electronic records or another database, send a letter to all inmates with diabetes informing them of the study; specify in the recruitment flyer that inmates with diabetes not on insulin are welcome to participate.

Gender inequity which can lead to sampling bias was an issue in this study. For this case study example, there were only six female participants (N=124) with a ratio of male to female participants of 20:1. The small number of female participants was likely a product of the composition of the state prison population and does affect generalization of the study findings to women. Worldwide, the female incarcerated population although not as large as the male prison population has grown (BJS, 2006; Gainsborough, 2008). Research supports that female inmates have higher rates of mental health problems (BJS, 2006), premature mortality (Massoglia, Pare, Schnittker, & Gagnon, 2014), and a long history of pre-incarceration addiction, domestic

violence and victimization when compared to male inmates (Kuo et al., 2013; Stockman, Lucea, & Campbell, 2012). In addition to ensuring adequate representation of incarcerated women in research, it is important to examine the influence of these characteristics on self-care management for diabetes and other chronic illnesses. Research modifications include: collaborating across state and international boundaries to allow for more equal representation of female inmates in research; conduct more participative action or narrative inquiry research not dependent on large sample size but will still help to enhance understanding of variations in care for incarcerated women.

### **Data Collection Challenges**

Many of the participants in this study reported having vision impairment or an eye problem. One participant had to return to his cell to retrieve his glasses because he could not clearly read the informed consent. Sending participants back to their cell to retrieve reading glasses was not an easy task. Inmates required passes to come to and from the study interview. On one occasion, the researcher had to come back on another day to meet an inmate who went back to his cell to get his glasses. Several times during the day there are scheduled periods of restricted or no movement within the prison. Correctional officers who are responsible for maintaining safety and security must adhere to these policies. Researchers who are guests in the system must also comply and be understanding and patient as well.

In the current study, all participants had diabetes and 66 % (82) of 124 participants had hypertension. In 2005-2008, the Centers for Disease Control [CDC] (2011) reported that 4.2 million (28.5%) persons with diabetes age 40 and older had diabetic retinopathy. Hypertension is an independent predictor of retinopathy (Della Croce & Vitale, 2008; Klein, Myers, Lee & Klein, 2010). Recent evidence suggests that hypertension and diabetes have synergistic effects

on retinal microvasculature resulting in endothelia dysfunction and retinal microvascular changes (Mohammed et al., 2012). Additionally, glaucoma and ocular trauma have been found to be more prevalent in inmates and oftentimes in the case of ocular trauma more severe than in non-incarcerated patients (Trivedi, Wu, Leffler & Schwartz, 2003; Wu, Leffler, Pastel, Schwartz & Allen, 2003). For the current study, the researcher used large font print for the recruitment flyer and the REALM health literacy instrument. Many of the participants commented on their preference for the larger font.

Based upon this evidence and observations from this study, researchers should make modifications to account for anticipated vision impairment in this population. This is essential to protect the rights of this vulnerable population and maintain adherence to Institutional Review board (IRB) guidelines. Research modifications include: Providing instructions to inmate participants especially those with diabetes or hypertension to bring their glasses for the consent process and other research related procedures; and providing large print documents to inmate participants is also advised.

### **Communication Challenges**

The potential for issues with communication exists from inception of the research question to the dissemination of results. Identified strategies for enhancing communication include: having a contact person or “champion” within the organization, concordance among stakeholders with issues requiring solutions and questions needing to be addressed, and allowing ample time for planning of the study (Cislo & Trestman, 2013; Wakai et al., 2009). A great deal has been said in the literature about the affect of the research on the general operations and flow of the correctional facilities. However, being considerate to the needs of the potential inmate participants is also important.

For this study, inmates completed a medical request slip in order to notify the researcher that they were interested in hearing more about the study. Consent, enrollment and data collection took place on the spot and during one visit. On a few occasions throughout this study, inmates were being called down for the study interview during recreation or shower time or near the end of the medication administration time period. When called down to meet with the researcher, oftentimes the inmate was not aware of why he was being called down to the medical care area. Communication between the researchers and the correctional officers must be underscored. Considering that inmates usually only have restricted time out of the cell for recreation, meals, and medication administration line, researchers must be considerate of their situations. Oftentimes, inmates may have only an hour for outside recreation. Having a good relationship with the DOC and nursing staff is helpful for coordinating these efforts and minimizing these intrusions.

An important area for communication when conducting research with inmates with diabetes is in regard to the prevention of adverse outcomes associated with the occurrence of hypoglycemia. Most researchers working with participants who have diabetes are well aware of the potential for hypoglycemia. However, there are some additional considerations when working with inmates with diabetes and especially with inmates on insulin.

In this study, 60% of 124 participants surveyed responded that they “rarely” or “never” carried a fast acting sugar to counteract the effects of hypoglycemia. Forty percent (n=49) of the participants could not correctly identify the signs and symptoms of hypoglycemia. If the interview or study procedures were completed at a time when an inmate could not return to his/her cell, the inmate would need to sit in the waiting area until the movement restriction was lifted. With these cases, researchers must be aware of the appropriate channels or chain of

command for notifying nurses or correctional officers that the participant might be at risk for hypoglycemia if left in the waiting room for an extended period of time. And if the inmate was not carrying a fast acting sugar to counteract the effects of hypoglycemia, this information would also need to be communicated. During this study, there were occasions when inmates were sent for the interview before or after dinner, sometimes after insulin administration but before dinner or after recreation, potentially high risk times for hypoglycemia. The researcher made a point of asking the inmate if the study interview was going to interrupt meal time or medication administration. On one occasion, the researcher sent the inmate to dinner. Only on one occasion did the researcher need to notify a nurse that the inmate was reporting symptoms of hypoglycemia.

Last, calling ahead or having a contact within the system to call you is important for the researcher's time management. Lockdowns due to a problem in the system can happen often. During this study, a nursing supervisor, identified as my contact, from one of the participating facilities called the researcher on two occasions with notification of a lockdown and advised the researcher not to come to the facility. This study was conducted in five facilities across the state so travel could require more than a fifty minute commute each way. Research modifications include: timing of research activities to avoid interrupting the usual insulin administration and meal schedule; calling the facility prior to traveling or establishing a call notification with an onsite contact obtaining approval for and providing refreshments that support diabetic health. The latter modification could be problematic if it was viewed as an incentive and would need to be approved by the IRB and the DOC.

## **Discussion**

Conducting research with inmates diagnosed with diabetes requires attention to a set of safety and methodological concerns above and beyond that of the ethical and legal regulations for protecting the rights of this vulnerable population. Researchers must consider the needs of inmates with diabetes- pathophysiologic and the effect of prison. Researchers designing these studies need to blend their knowledge of diabetes with an understanding of prison culture and the rules. Researchers unfamiliar with the correctional setting or external to the system must consult and collaborate on all levels including with administration, correctional officers and nursing.

Policies and procedures that could affect the recruitment of an adequate sample, safety issues related to hypoglycemia, infringement on inmates already limited time out of the cell need to be factored in when developing the research proposal. In addition to the researchers responsibility for ensuring the safety of inmates with diabetes during the research process, Organizations caring for these individuals should have policies in place that allow for inmates to carry fast acting sugar to counteract hypoglycemia and that provide guidelines for correctional staff working with inmates who have diabetes.

Furthermore, inmates should be involved in the research process especially when designing interventions and developing instruments. In a maximum security prison in England, Cowburn and Lavis (2013) described the use of a participatory research approach to explore the experiences of prisoners in diverse minority groups and the prison strategies for meeting the needs of this group. They used “reciprocal collaboration” (Gottesdeiner, 2002), an approach that gives inmates the opportunity to form and contribute ideas and solutions to identified problems. Although engaging inmates in this manner may seem counterintuitive, this type of research has the potential to not only improve care and inmate buy in for policy or care delivery changes but

also to enhance inmates' problems solving and communication skills. Enhancing these skills is especially important for diabetes self-management and has been the focus of much research with community dwelling individual with diabetes. It is possible that diabetes or chronic illness research or quality improvement initiatives using participative processes are occurring in various local and state departments of corrections organizations. However if this is the case, it is not apparent in the literature. Publishing or sharing the experiences of using these approaches should be required on an international and national level.

It is critical that funding agencies be made aware of these issues and plans for managing these issues when conducting research with inmates and in a prison setting. Providing feedback to funding agencies about these issues at the onset of the research and ongoing throughout the project will give funding agencies an opportunity to adjust timelines for research completion. Requesting no-cost extensions when research deadlines are not met should be included in all grant submissions. As noted in this study and others, the problem with recruiting female participants requires innovative and likely lengthy recruitment and oversampling procedures .

### **Conclusion**

Research with inmates who have diabetes is especially challenging. Research conduct in this area is needed for all aspects of the incarceration experience from entering the prison through re-re-entry and reintegration to the community. Although research, especially experimental and RCT, is desperately needed to improve diabetes related outcomes and self-care behavior for this vulnerable population, researchers must conduct rigorous and well thought out research with respect to the needs of the all parties involved. Having an understanding of what the issues are and making modifications increase the opportunities for conducting rigorous as well as facility and inmate friendly research.

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## CHAPTER IV

### Rediscovery of Self-care for Incarcerated Persons with Diabetes

Louise Reagan, MS, APRN<sup>1</sup>

Deborah Shelton, PhD, RN, FAAN<sup>2</sup>

Elizabeth Anderson, PhD, APRN, FAAN<sup>3</sup>

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### **Abstract**

**Purpose:** To examine self-care for diabetes in the incarcerated population within the framework of the Rediscovery of Self-Care (RSC), a newly developed care model for persons with incarceration experience.

**Organizing Construct:** Diabetes is a chronic illness that requires the development and use complex self-care management skills. The RSC, a developing care model for persons with an incarceration experience, is a strengths-based model with the foundational assumption that nurses, interprofessional care providers and inmates believe that inmates are capable of re-discovering their own strengths for self-care.

**Findings:** Persons with an incarceration experience have person and environment factors that can enhance or impede self-care for diabetes. Using a case management and clinical assessment approach, nurses and interprofessional care providers can assist incarcerated persons with re-entry and re-integration into the community by decreasing vulnerabilities and promoting adaptation, self direction and the re-discovery of self-care.

**Conclusions:** Diabetes self- management is a requisite skill for improving health outcomes in persons with diabetes. Incarcerated persons with diabetes have numerous multilevel challenges to engage in diabetes self-care management. Because of this they are at risk for poor health outcomes while in prison and upon re-entry into the community. Nurses and interdisciplinary case managers or care providers using the RSC to guide the re-discovery of diabetes self-care can improve diabetes related and re-entry outcomes for incarcerated persons.

**Clinical Relevance:** Nurses and other health professionals have an opportunity to promote and enhance self-management for incarcerated persons with diabetes. Theory based approaches for

guiding nursing practice and research in the area of self-care management for this vulnerable population are lacking.

**Keywords:** Inmates, incarceration, self-care, diabetes. self-management

## **Background**

Diabetes occurs in the prison population at similar or slightly greater prevalence than in the community dwelling population (Binswanger, Kreuger, & Steiner, 2009; Wilper et al., 2009). The current estimated diabetes prevalence of 4.8% is predicted to rise (American Diabetes Association [ADA], 2014). Engaging in self-care behavior (SCB) for diabetes is integral to achieving good glycemic control and reducing the incidence of complications (AADE, 2010, 2014; ADA, 2014; Kolb et al., 2012).

Diabetes self-management education and support helps persons with diabetes initiate and maintain important SCB and improves disease outcomes (ADA, 2014; Haas et al., 2013; Norris, Engelgau, & Narayan, 2001; Norris, Lau, Smith, Schmid, & Engelgau, 2002). Both the ADA (2014) and National Commission on Correctional Health Care (NCCHC) (2013) acknowledge the challenges for providing comprehensive diabetes care and diabetes self-management education to incarcerated individuals. There is little evidence as to what constitutes effective diabetes self-management education (DSME) in the correctional setting.

Incarcerated person with diabetes have numerous external and internal barriers, different from persons with diabetes living in the community, to engaging in self-care for diabetes and participating in effective diabetes self-management education and support. Stringent prison rules for safety and security, inmates' co-existing mental illness, addiction disorders, and various sociocultural and literacy issues complicate the delivery of diabetes self-management education and inmate engagement in diabetes self-care.

None the less, persons entering or reentering the correctional system do so with a certain set of skills even if some skills, possibly those related to their criminal activity, are misguided or misdirected. The RSC (Shelton, 2011; Shelton et al., 2009), a developing care model for persons



with an incarceration experience, is a strengths-based model with the foundational assumption that nurses, interprofessional care providers and inmates believe that inmates are capable of re-discovering their own strengths for self-care. Therefore, the RSC provides an excellent framework for enhancing preexisting skills and developing new SCBs for inmates with diabetes.

Shelton's et al. (2011) model can be applied to any aspect of self-care. However, it generally refers to self-care as a holistic process which leads to problem-solving and goal oriented behavior for the inmates during times of transition such as entering prison, learning to sustain wellness while incarcerated, or reintegrating into society. Along the continuum of the incarceration experience, the inmate would need to develop and/or adapt self-care in many areas in order to be prepared to manage his/her health during or post incarceration. Promoting and maintaining diabetes SCB would be only one component of an inmate's rediscovery of self-care. Achieving good glycemic control is critical to maintaining good physical health (ADA, 2014). Poor physical health and concerns about physical and mental health can pose threats to reintegration into society (Mallik-Kane & Visser, 2008; Woods, Lanza, Dyson, & Gordon, 2013).

### **The Rediscovery of Self-Care (RSC) Model**

The RSC, a model for persons with incarceration experience (Shelton, 2011; Shelton, Barta, & Anderson, 2009), provides a framework for interprofessional care providers (nurses, primary care providers, psychiatrists, social workers and more) to assess, intervene, and evaluate inmates in all phases of the incarceration experience. Re-entry and eventually reintegration into the community, both components of the incarceration experience, and the ability to sustain effective self-care are the desired outcomes of this care model (Shelton, 2011; Shelton et al., 2009). Although it can be used for any area where self-care is desired or required, for the

purpose of this paper we will discuss the approach to self-care for diabetes. A brief discussion of the model is provided.

The RSC model is grounded in Orem's definition of self-care and concepts from Richardson's (2002) metatheory of resilience. These authors view self-care as an action directed by individuals toward themselves or their environments for the purposes of regulating their own functioning and sustaining life under their changing environmental conditions (transition into, through, and out of prison). Further, actions designed to maintain or bring about a condition of well-being are also targeted goals. Richardson's (2002) conceptualization of resilience as a capacity that everyone possesses and acts as a motivator in times of disruptive events is beneficial to achieving adaptation and reintegration into the community following incarceration. Shelton et al. (2011) identify resilience related factors of self-efficacy, motivation, perceived control and the ability for planning or being able to select and choose self-care activities as critical. Persons entering, living in or exiting prison may experience a disruption in the ability to engage in self-care. Nurses using the RSC model would seek to increase self-care by increasing resilience related factors and reversing or preventing the deskilling and infantilization that takes place in persons as a result of incarceration experience.

Figure 1 provides a schematic of the RSC. Shelton et al. (2009) identifies psychosocial, demographic, and individual factors (e.g. mental health, personality, marginalization, hyper vigilance, motivation) as well as personal transitions through non-binding stages (vulnerabilities, adaptation, self direction and self-care) and environments (community, prison, initial re-entry and re-entry/re-integration) that may impede or enhance an inmate's ability to develop and maintain self-care. In earlier work, Shelton (2010 a, b) examined stress and vulnerabilities of persons with an incarceration experience. She notes that historic and repeated stressors among

persons with a personality disorder and burdened by vulnerabilities (such as prenatal risk, cognitive limitations, disorganized and poor communities, PTSD, childhood abuse) enhance maladaptive behaviors. Poor outcomes for self-care management, taken broadly, include a range of biological, psychological, social and criminal outcomes. Combined with overburdened court systems, poorly written and executed laws, Shelton (2010 a, b) points out and the Bureau of Justice (2012) confirms that 47% of inmates incarcerated for non-violent offenses could be treated in alternate and less restrictive settings thus avoiding the added stressor of incarceration and further reduction in self-care.

Furthermore, Shelton et al. (2009) provides interventions for care and coordination (e.g. assessments, provision of support, treatment referrals) necessary to assist the inmates with transitions through the phases- vulnerabilities, adaptation, self direction and self-care. The model is bidirectional and dynamic. The RSC takes into account that at any given time during the incarceration experience, persons may flux between the phases of vulnerabilities, adaptation, self direction and self-care. Nurses and interprofessional care providers adjust interventions for clinical care and case management coordination based upon the strengths and needs of the individual, the setting/environment and situation. The next section reviews each phase of the RSC model and utilizes findings from the literature and research with incarcerated persons with diabetes (Reagan, 2014) as an applied clinical case study.

### **Phase 1: Vulnerabilities**

The focus for the first phase of the model is acknowledgment that incarceration is a disruptive life event known to be associated with multiple stressors and threats to self-care (Haney, 2001; Turney, 2013-2014; World Health Organization [WHO] & International Association for Suicide Prevention [IASP], 2007). During times of transition, nurses and other

interprofessional care providers have the opportunity to assess the self-care skills and capabilities of the incarcerated person. Basically, the nurse is taking stock of the inmate's strengths and weaknesses while acknowledging that this is a time of considerable stress.

The nurse and case manager must have an understanding of both vulnerability factors and stressors. Ingram and Luxton (2005) describe vulnerability factors as predispositional factors that place the person at risk for a disordered state (p. 34). Shelton et al. (2011) classifies vulnerability factors related to the person and environment that could positively or negatively affect the incarcerated person's ability to engage in self-care at each phase of the incarceration experience. For the vulnerabilities phase, person related factors are described as being related to life history including life circumstances, past medical and psychiatric history, personality, vocational or interpersonal skills. Environment related factors are described as community factors including socioeconomic status, (dis)advantage, victimization, and marginalization. The clinical assessment and case management process will increase the nurses and interprofessional care provider's understanding of the inmate's current level of vulnerability – the sum total of factors known to increase or decrease the resilience related factors of perceived control, motivation, self-efficacy and planning for self-care. This clinical assessment process will help to identify case management needs and promote coping behaviors.

To maintain good diabetes control and health, persons with diabetes must engage in many SCBs. Self-care for diabetes includes healthy eating, being physically active, self monitoring of blood glucose (SMBG), medication taking, problem solving, and reducing risk including smoking cessation and attending annual eye and foot exams (AADE, 2013, 2014). Healthy coping which includes having motivation and healthy coping skills is the last SCB (AADE, 2014). Persons with an incarceration experience may be performing all of these or none of these

self-care behaviors depending on where (s)he is on the continuum of the incarceration experience. Transitioning from the community to prison, an incarcerated person may feel a sense of relief that his healthcare and medications are provided, or on the contrary may experience loss of control over not being able to manage diabetes on his/her own terms (Condon et al., 2007). For example, a person who has never been incarcerated, had good support systems, intact cognitive functioning, a job and health insurance prior to incarceration and suddenly loses the ability to perform self-care may perceive this as a significant stressor, and according to the RSC a threat to his perceived control. In the assessment, it would be important for the nurse to identify these strengths and develop a plan that maintains or encourages self-care skills that will be allowed in the prison environment. It is equally important for the nurse to maximize preexisting SCBs as it is to develop new SCBs.

Co-occurring disorders are common among this population. Unfortunately, inmates have a high burden of chronic disease such as cardiovascular disease (Arries & Maposa, 2013), diabetes, hepatitis (Binswanger, Stern, & Deyo, 2009; Herbert, Plugge, Foster, & Doll, 2012), and many, being from communities with a high burden of health disparities, are also from a lower socioeconomic status (Borysova, Mitchell, Sultan, & Williams, 2012). Additionally, as many as one in seven prisoners have mental illness (Fazel & Danesh, 2002), co-occurring mental health disorders (Fazel & Baillargeon, 2011; James & Glaze, 2006; Kessler & Wang, 2008) and a substance abuse history or addiction diagnosis (James & Glaze, 2006; Woods, Lanza, Dyson, & Gordon, 2013). The combined effects of life history and pre-incarceration environment have the potential to affect perceived control, motivation, and self-efficacy for self-care and the ability to plan for and engage in self-care. These vulnerabilities can occur at any stage but are more likely

to occur during transition phases such as entering incarceration, changing facilities or being ill prepared for re-entry.

## **Phase 2: Adaptation**

The focus of this phase is on helping incarcerated persons adapt to prison while maintaining or developing new self-care skills. For incarcerated persons with diabetes, adapting to the prison may mean changing one's insulin regime, having insulin administered to you rather than by you, curtailing physical activity or eating unfamiliar foods. Vulnerability factors identified in Phase 1 and cognitive function will influence how the person responds and adapts to the stress of incarceration and to other changes in usual self-care regimens.

Nurses and members of the interdisciplinary team work collaboratively to evaluate the inmate's cognitive function. Many inmates have chronic stress from pre-incarceration issues such as substance abuse (Binswanger et al, 2012; Calcaterra, Beaty, Mueller, Min & Binswanger, 2014), untreated or serious mental illness, chronic health conditions (Wilper et al., 2009), prior physical abuse, intimate partner violence and/or repeated incarceration (Haney, 2002). Cognitive functions such as memory and executive function is adversely affected by chronic stress (Cavanaugh, Frank, & Allen, 2010; Yuen, et al., 2014). To facilitate adaptation to the prison environment, inmates with cognitive impairment need to be identified and have treatment maximized.

The prison environment and the effects of institutionalization often referred to as "prisonization" when used in the context of inmates are person and environment factors that the nurse should address during this phase. These factors can affect the inmate's identification and perception of stressors and the ability to use available support systems in or outside the prison (Shelton, 2010a, b; Shelton et al., 2009). Some inmates respond to the highly controlled prison

environment and inmate culture by exhibiting signs of withdrawal, dependency and hyper vigilant behaviors (Haney, 2001; Shelton, 2010a). Additionally, personality e.g. neuroticism has been linked to the tendency to appraise an event as stressful (Gunthert & Cohen, 1999) and use maladaptive coping strategies including emotion focused and social withdrawal (Connor-Smith & Flachsbart, 2007). Inmates with certain types of personality characteristics or a mental health issue may have distorted perception and overestimate the extent of the stressor and as a result experience a decline in self-care (Shelton, 2010). Multiple vulnerabilities will have greater influence on how the inmate appraises and adapts to the stressor.

Alternatively, during this phase inmates may benefit from growth promoting aspects of confinement. Given the close quarters of most jail and prison cells, inmates can benefit from having social support that is greater than what was experienced in the community. Case in point, an inmate participating in the evaluation of a prison Group Medical Appointment (GMA) communicated a story that supported the growth promoting aspect of prison (Reagan, 2011). The inmate who had English as a second language (ESL) recalled that early in his incarceration and prior to being diagnosed with diabetes, he “was sweating and urinating a lot”. He stated that he did not recognize that these symptoms were associated with diabetes. He did not perceive the symptoms as a problem but thought that he was drinking large amounts of water and exercising too much. These symptoms were not identified or perceived as a stressor because the inmate lacked knowledge of the signs and symptoms of diabetes. However, when another inmate told him that he should “get checked for diabetes”, he immediately went to the prison medical unit at which point he was diagnosed with diabetes. The social support provided by one inmate and accepted by another inmate illustrates the growth promoting aspect of prison. When examining the interpersonal relationships of inmates, Wulf-Ludden (2013) found that male and female

inmates reported not only having friendships in prison but also that other inmates helped them make improvements in areas of their life.

While assisting the inmate to navigate the system and identify necessary self-care behaviors, the nurses and the interprofessional care providers should engage with inmates to identify and clarify goals for improving self-care for diabetes. These goals should be realistic given the inmates stressors e.g. new to insulin, fear of needles, lack of social support, lack of knowledge about hypo and hyperglycemia and vulnerabilities (lack of health literacy, physical and mental disabilities, addiction disorders, multiple chronic medical conditions etc). As soon as the incarcerated person's vulnerabilities have stabilized and (s)he has adapted to the prison setting, re-entry preparation should begin.

### **Phase 3: Self-Direction**

This phase is an important one in that it establishes a strong foundation for successful transition or re-entry into the community. Because self-care is a holistic process, nurses and interprofessional providers assist inmates with self-care related to many areas such as securing housing, accessing outpatient mental health and primary care and substance abuse programs. Although this paper discusses the processes related to diabetes, techniques that increase goal setting, problem solving, emotion control for other aspects of self-care can be effective. Cognitive behavioral therapy, motivational interviewing, and Wellness Recovery Action Planning (WRAP) (Cook et al., 2013; Cook et al, 2011) techniques have been found to be effective in increasing self-care of mental illness and substance abuse issues. Cognitive behavioral therapy has been effective for improving adherence to medication, depressive symptoms and glycemic control (Safren et al., 2014).



The interprofessional team should also prepare inmates for other transitions such as transferring within the system to prisons with lower level of security. As a result of this type of transition, inmates may gain some new privileges such as more time for outside recreation or the ability to keep approved medications in his/her cell. However, if the inmate is not self directed to seek solutions to problems that arise as a result of this transition (transfer) (s) he could experience a decline in self-care for diabetes and other areas of his life where self-care is required.

To illustrate this phenomenon, the author presents the following experience that occurred during a research study involving inmates (Reagan, 2014). As a component of this research study, inmate participants who consented to be in the study were asked about their performance of diabetes self-care behaviors. While answering questions related to the performance of checking blood glucose, a participant commented that (s)he used to check the blood glucose at another facility. However, after transfer to the current facility (s)he indicated that (s)he was no longer called down to medical to have his/her blood glucose checked. The inmate made no effort to ask the medical staff about the reason for the change in the plan of care; (s)he thought that this was the predetermined plan of care at the new facility.

In examining this inmate behavior with the RSC, the transfer to the new prison, in this case a transition and disruptive event resulted in a decline in the inmate's perceived control and ability to secure resources and thus plan for continued diabetes self-care. The inmate identified that there was a change in an aspect of his diabetes care but did not appraise this as a problem, or identify the change in routine as a cue to seek solutions. Multiple factors such as cognitive or emotional vulnerabilities of the inmate, lack of social support in a new environment, or system

issues due to poor nursing and team communication with the inmate and other facilities could have influenced this situation.

For inmates with diabetes, having the ability to identify the signs and symptoms of hypo/hyperglycemia (situation awareness) is a life sustaining self-care skill. Essential components of this skill include having knowledge of the signs and symptoms and an awareness of the personal cues that signify a high or low blood sugar. In a study examining the relationship of diabetes knowledge, self-care behavior and illness representations with respect to glycemic control, Reagan (2014) found that out of 124 inmates only 60.5% identified the signs and symptoms of hypoglycemia and 61.3% identified the signs and symptoms of hyperglycemia. Having insufficient knowledge about hypo- and hyperglycemia is a barrier for developing self-care management for this problem. If the signs and symptoms are not readily attributed to a problem with the diabetes, the inmate will not be able to set appropriate goals and develop strategies for problem solving such as going to the medical clinic or checking the blood glucose.

Furthermore, some prisons do not allow inmates to have access to a glucometer. Inmates with this restriction might have difficulty with timely validation of symptoms and setting goals to manage these symptoms. Until recently, access to a glucometer was not allowed in most state correctional environments in the US. Preliminary findings from a quality improvement project in a US prison support that having KOP glucometers for selected inmates enhanced self-care and improved health outcomes (Ball, 2011). Allowing inmates access to glucometer would give nurses opportunities to work with inmates on developing and practicing skills for self-management of blood glucose monitoring (SMBG) prior to re-entry.

Additionally, there is some evidence of less restrictive glucometer and insulin policies at the international level. In an international qualitative study of inmates' views of prison health

services, Condon et al. (2007) noted that most of those surveyed were allowed access to glucometers for SMBG and administered their own insulin under the observation of a nurse (N=111 and total number of participants with diabetes was not specified). Even with less restrictive policies for some aspects of diabetes care, the inmate participants of this study perceived that prison rules dictated health care policies and decreased their autonomy to engage in healthcare (Condon et al., 2007). This finding suggests that inmates wish to be more involved in their diabetes care. This study did not address safety issues or problems associated with inmates performing these SCBs.

Because incarcerated persons can vacillate, seen in the bidirectional flow of in the RSC model, between using negative behaviors and ineffective coping for the dependent “prisonized” role and positive behaviors and effective coping needed for successful transitions and re-entry, nurses need to educate inmates to be better consumers of health care. Nurses and case managers can help inmates maximize self-direction by building upon and maintaining the inmate’s resilience related factors of self-efficacy, control beliefs, motivation and planning.

#### **Phase 4: Self-Care**

Nurses and the interdisciplinary care providers have important roles in helping the inmates to rediscover self-care. Oftentimes, it is not an easy one. Nurses, typically experts at developing nurse-patient relationships, have to balance the concerns of custody and caring when assisting incarcerated persons through the phases of the RSC. Assisting inmates toward self-care and preparation for release can be easily visualized through execution of the education role of nurses. Opportunities for teaching abound. For example, Reagan (2014) found that greater than 50% of inmates (N=124) surveyed did not know the normal value for the Hemoglobin A1C (A1C). Helping inmates to understand the meaning of the A1C before re-entry benefits the

inmate in so many ways. Nurses can teach inmates about the importance of maintaining A1C less than 7% to decrease their morbidity and mortality. Greater than 80% of inmates (N=124) surveyed knew the complications of diabetes. Possibly if they understood the association of poor glycemic control or high A1C to specific complications, they might be motivated to keep the A1C to less than 7%. If inmates understand what the A1C means, nurse can teach inmates how to set goals for lowering or maintaining and to problem solve when the A1C is high or worsening.

Discussing with inmates situations that they will be confronted with and decisions they will need to make related to diabetes as well as other aspects of self-care assists them with visualizing their re-entry to the community. Shelton et al (2010 a, b) found that the use of structured workbooks to assist inmates in their thought processes was an effective strategy both within and outside the prison. The Connecticut Offender Re-entry Program (CORP), collaboration between the Connecticut Department of Mental Health and Addiction Services (DMHAS) and the Connecticut Department of Correction (CDOC) is an example of this type of programming. With an emphasis on reducing recidivism, CORP provides culturally appropriate intensive case management, integrated mental health and substance abuse treatment services, and linkages for men and women to their community 6-12 months prior to release from DOC (Kesten et al., 2012; Pagano, Leavitt-Smith, Rau, Shelton, Zhang & Trestman, 2012).

### **Recommendations for Practice and Research**

Diabetes self-care management is essential for successful re-entry into the community. Inmates with chronic illness are at risk for substance abuse relapse and reincarceration (Binswanger et al, 2012). Effective interventions to enhance factors antecedent to diabetes SCB such as self-efficacy (Krichbaum, Aarestad & Buethe, 2003), goal setting (AADE, 2014),

problem solving (Hill-Briggs & Gemmell, 2007) are abundant in the literature. Many of these interventions have been found to enhance many skills for self-care (Newlin Lew, Nowlin, Chyun & Melkus, 2014; Norris, Engelgau, Narayan, 2001). The interventions are multifaceted and often have been examined in diverse community dwelling participants who have one or more chronic illnesses. Less research and quality improvement initiatives has been conducted in the prison or with recently incarcerated individuals. Moreover, the community based research has not been appropriately modified to account for the context of prison and the effect of incarceration.

Being mindful of the distinctive set of psychological adaptations that often occurs in response to the demands of prison life involves the incorporation of the norms of prison life into an inmate's habits of thinking, feeling, and acting. As a result, adaptations may include behaviors that challenge support of self-care behaviors: such as the relinquishment of autonomy; interpersonal mistrust and suspicion; social withdrawal and isolation; and diminished sense of self-worth and personal value. These prisonization effects jeopardize the positive personal and behavioral coping adaptations required for self-care and successful transition from prison and reintegration into society.

The RSC is an easily applied model that incorporates inmate assessment, and dynamic movement through various phases and environments of the incarceration experience. Researchers have opportunities to develop protocols to test constructs for each phase of the model. Because it is common for patients or inmates to have multiple conditions that require self-care management, researchers could use the RSC model to organize interventions and care for multiple chronic physical and mental health conditions. Some of these constructs or themes have already been examined in non incarcerated populations. An integrative or systematic

review of these interventions within the framework of this model might be helpful for determining the direction for future research on self-care for the incarcerated population.

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Figure 1

## Rediscovery of Self-Care: A Care Model for Persons with Incarceration Experience

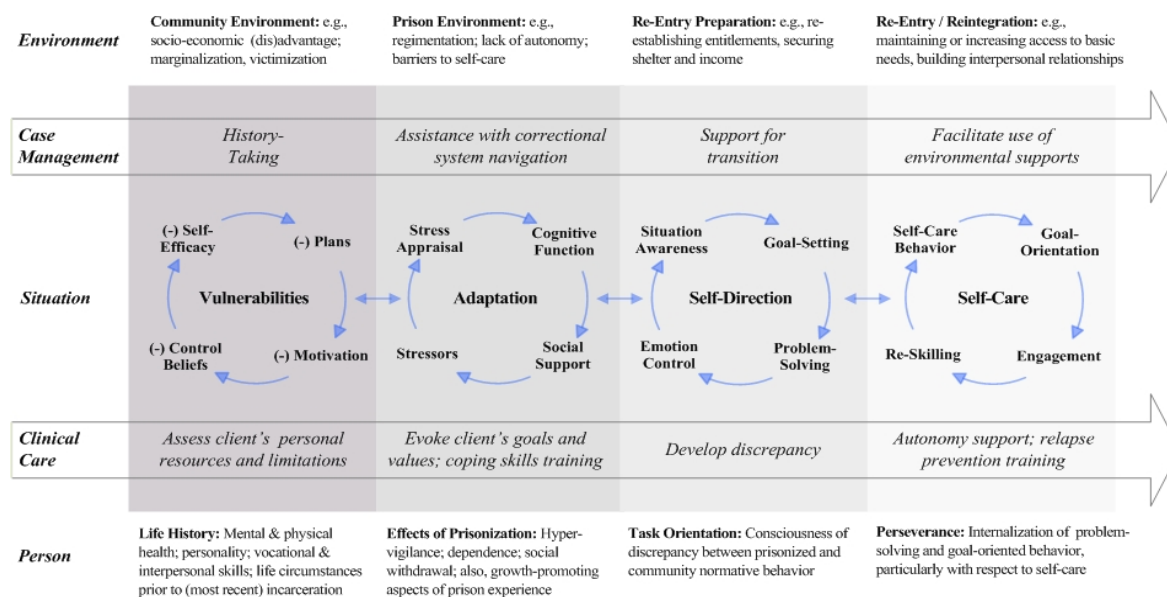


Figure 1. The phases of the RSC illustrate how interprofessional care providers (case managers and clinical care providers) support a process that help an inmate with multiple vulnerabilities e.g. low self-efficacy, low motivation, decreased personal control and no plans upon entering prison adapt to a highly restricted and stressful prison environment and ultimately transition through to an engaged goal directed individual capable of self-care in the less restricted community environment. The bidirectional arrows between phases indicate that inmates often flux (relapse) between different phases; directional arrows within each phase indicate that this process is dynamic requiring ongoing assessment and intervention related to key variables or themes within each phase. Interventions are adjusted according to the phase that the inmate is determined to be in but always with the intent to enhance the resilience related factors of self-efficacy, planning, motivation, and personal control.

(Reprinted from Shelton, D., Barta, W.D. & Anderson, E. (2009). University of Connecticut.

## **CHAPTER V**

### **Conclusion**

In this chapter, I will review key findings from each of the three papers. Following this summary, I will synthesize the findings and theoretical underpinnings from all three papers into a cohesive whole through a discussion of the implications for practice and recommendations for research.

#### **Review of Findings**

**Article 1.** Nearly half of the inmates in this study had inadequate health literacy and the majority reported a history of substance abuse. The findings from this study indicate that incarcerated persons with diabetes have knowledge deficits in key areas such as knowing the normal fasting blood glucose and A1C value. Important self-care behaviors such as carrying a fast acting sugar to counteract the effects of hypoglycemia are not being performed with great frequency. These findings related to the performance of SCBs and knowledge about diabetes can negatively impact the inmate's ability to problem solve, set goals and engage in SCB- all fundamental processes for effective self-care management. Inmates participating in this study are at increased risk for the development of micro- and macrovascular complications and life threatening hypoglycemia as a result of not performing important SCBs and having diabetes knowledge deficiencies in critical areas and poor glycemic control, .

Lower personal control beliefs, greater self-report of diabetes understanding and being on insulin were predictive of higher A1C or worse glycemic control. Higher personal control beliefs were associated with lower A1C. Similar to the findings from this study, having beliefs that diabetes can be controlled is predictive of lower A1C or better glycemic control in community dwelling individual with diabetes.

**Article 2.** The unique characteristics of the correctional setting and inmates with diabetes require that researchers modify methods for conducting research with this vulnerable population. Methodological challenges for conducting research with incarcerated person with diabetes include sampling bias due to gender inequity, inadequate recruitment of participants not on insulin, lack of standardized instruments, potential for patient safety issues associated with risk of hypoglycemia, vision impairment of participants affecting informed consent and data collection procedures, interpreter requirements, and ineffective communication among all stakeholders. Opportunities for making modifications to the research exist and if implemented will improve research rigor and allow for the development of intervention research and RCTs.

**Article 3.** Incarcerated persons with diabetes have many personal vulnerabilities e.g. mental illness and addiction disorders, poverty, low health literacy and cognitive impairment and environmental factors e.g. prison culture, custody and security policies that can constrain self-care for diabetes. Reagan (2014) identified some of these factors when conducting research with inmates. It is important for care providers and researchers to understand what these factors are. Despite these threats to self-care, nurses, other interdisciplinary care providers and inmates recognize that inmates have the capability to rediscover self-care. The RSC (Shelton, 2011; Shelton, Barta & Anderson, 2009), a theory and strengths based approach for rediscovering self-care, provides a framework that allows for a comprehensive assessment and identification of factors that potentially render the inmate incapable of self-care for diabetes. The RSC model illustrates nonbinding phases of the incarceration experience and thus allows for the development and implementation of phase specific interventions. Interventions are directed at enhancing inmates' self-efficacy, motivation and personal control for self-care and at enhancing abilities to plan for self-care. Nurses and interprofessional care providers can work together to help inmates

move from being disengaged to engaged in a rediscovery of self-care. As inmates reenter society, being able to self-care for diabetes and other health problems should increase opportunities for a smooth transition to the community and eventually reintegration into society.

### **Implications for Practice**

Statistics and demographics presented in this dissertation illustrate that incarcerated persons are among the most vulnerable persons in our society. They are large in numbers with an overrepresentation of ethnic minorities and as a whole less healthy than persons living in the community who have not had an incarceration experience. They have many chronic health needs as a result of living with multiple coexisting chronic illnesses. Even inmates themselves perceive their health as poor (Hickey, Kerber, Astroth, Kim, & Schlenker, 2014).

Diabetes is just one of many chronic illnesses with which inmates must cope. Persons living with diabetes have an enormous responsibility for self-care probably more than for most other chronic illnesses. In the community, persons with diabetes manage 95% of their care (Pearson, Mattke, Shaw, Ridgely, & Wiseman, 2007).

Comprehensive, coordinated health care and patient self-management education will decrease diabetes associated morbidity and mortality (ADA, 2014). Providing such care and education to inmates has the potential to improve fiscal and individual inmate re-entry outcomes (Leddy, Schulkin, & Power, 2009; Mallik-Kane & Visser, 2008). Moreover, these practices will likely benefit the public health of the community to which the prisoner is released (Mallik-Kane & Visser, 2008).

Inmate participants in the current study were performing some self-care behaviors with greater frequency than others. Nurses and interprofessional care providers have many opportunities to provide care, education and skill development to inmates with diabetes. Using



the RSC model as a guide, nurses can assess inmates' motivation and self-efficacy for engaging in self-care. There are numerous simple and safe options for enhancing education and improving self-care in this population. A one item health literacy screener, found to be valid in community dwelling populations (Morris, MacLean, Chew, & Littenberg, 2006), could be performed on all first encounters with inmates. The one item for this brief health literacy is: How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy? (Morris et al., 2006) Making this a routine practice fits well within the RSC framework. Because low health literacy is one of the vulnerabilities that negatively impact self-care upon entry into prison through to re-entry to society, health literacy screening is needed for all inmates. Further validation of this health literacy screener is needed in the incarcerated population.

As has been suggested in the literature (Broadbent et al., 2006 ), the BIPQ which takes less than two minutes to complete could be administered to assess the inmates personal control beliefs, beliefs about etiology and chronicity and other domains of illness representation related to diabetes. Nurses and interprofessional care providers could use this information to collaborate and develop a plan of care for the inmate with diabetes.

Instead of nurses assuming responsibility for documenting blood glucose readings, inmates could be taught to keep a record of their blood glucose readings. When it is high, they should reflect on what they ate or drank in order to provide meaning to the blood glucose measurements and to allow for setting goals to decrease, increase or maintain blood glucose levels. Having inmates perform return demonstration when learning how to use a glucometer or inject insulin does require nurses to consider and plan for safety surrounding these

demonstrations. This level of self monitoring may not be appropriate for all inmates. Nurses, correctional officers and DOC administration should develop criteria that outline which inmates could have access to glucometers and be allowed to self-administer insulin under the observation of nurses.

Nurses should develop policies that require all inmates with diabetes who are taking insulin to carry a fast acting sugar. Ensuring that inmates have in their power the ability to carry a fast acting sugar is probably even more important in prison than in community dwelling settings. Additionally, correctional officers should be educated to recognize the signs and symptoms of diabetes. This could be easily operationalized as the ADA already has a curriculum for this purpose (ADA, 2010). Having nurses decentralized in the units where inmates live would allow inmates access to immediate checks of blood glucose with any symptomatic episodes. Learning how to interpret blood glucose results while in prison and with the support of the nurse will increase an inmate's self-efficacy for performing this SCB. Considering that 40% of inmates in this study could not accurately identify signs and symptoms of hypoglycemia, education and skills training are needed to increase inmate engagement and decrease adverse outcomes related to hypoglycemia e.g. falls, transportation to emergency department or hospital admissions.

Nurses have the capability of improving the health and well being of this population. By incorporating the findings from the research study described in chapter 2 and using the RSC to guide care, inmates will be better prepared to self manage their diabetes and likely other chronic health problems when they reenter the community.

## **Recommendations for Research**

Research needs for this populations can be easily identified within the framework of the RSC model (Shelton, 2011; Shelton et al., 2009). Considering the findings from the current study and tenets of the RSC, research should be directed at increasing the beliefs that inmates hold with regard to their ability to control diabetes and to increasing the performance of diabetes SCB. Many of the constructs such as motivation (Shigaki et al., 2010), self-efficacy (Krichbaum, Aarestad, & Buethe, 2003), problem solving (Hill-Briggs & Gemmell, 2007) and goal setting (Naik, Palmer, Petersen, Street, Rao, Suarez-Almazor, & Haidet, 2011) situated in the RSC model are characteristics or behavioral strategies known to enhance the performance of diabetes self-care management or improve outcomes in community dwelling persons.

Translating some components of community based research interventions particularly those conducted with other vulnerable populations to the incarcerated population may be appropriate. For example, black female participants of a community based group DSME program that incorporated coping skills training (CST) and diabetes medical care showed sustained improvements in glycemic control for up to two years after program completion (D'Eramo Melkus et al., 2010). Components of this intervention may be especially beneficial to inmates with diabetes given their history of emotion focused coping (Connor-Smith & Flachsbart, 2007). This DSME and CST could be integrated into a Group Medical Appointment that has been previously used (Gallagher, LaFrance, & Neff, 2011) and evaluated with incarcerated persons with diabetes (Reagan, 2011). As mentioned earlier, pilot testing of instruments prior to embarking on large studies or RCT is very much needed. Conducting focus groups with inmates might prove useful when developing instruments and designing studies.

Peer led diabetes self-management education and training has shown promising results in community based research with persons who have diabetes and other chronic illness (Heisler, 2007; Lorig, Ritter, Villa, & Armas, 2009; Philis-Tsimikas, Fortmann, Lleba-Ocana, Walker, & Gallo, 2011). Peer-led diabetes education programs in high-risk Mexican Americans had greater improvements in glycemic control when compared with standard approaches (Philis-Tsimikas et al., 2011). Moreover, findings from peer led programs for inmates with HIV indicate that peer educators have greater acceptability and credibility with inmates than traditional educators (Grinstead, Zack, & Faigeles, 1999). Participants of the program as well as the peer educators were found to have higher rates of HIV screening (Ross, Harzke, Scott, McCann, & Kelley, 2006) and an increase from baseline of HIV related knowledge after completion of the program (Ross et al., 2006). Other researchers have found that the peer led education program increase the peer educators' self-esteem and increase the peer educators self-assessment of their teaching skills (Ross, Harzke, Scott, McCann, & Kelley, 2006). Additionally, the peer led program has been found to confer benefits to inmates not participating in the program and to be relatively low cost (Grinstead, Zack, & Faigeles, 1999; Ross et al., 2006).

Based upon the work of Grinstead et al. (1999), a five day Peer Educator Program was developed at the Center for AIDS Prevention Studies (CAPS) at University of California. This program has been in use since 1991. Adapting this seemingly sustainable program for education and research with inmates with diabetes and other chronic illnesses such as hypertension or asthma seems quite feasible. A similar model is being used in the community to deliver low cost ongoing diabetes self-management support (DSMS) to sustain the effects of the DSME. DSMS is defined as "activities that assist the person with prediabetes or diabetes in implementing and sustaining the behaviors needed to manage his or her condition on an ongoing basis beyond or

outside of formal self-management training” (Haas et al., 2012, p. 2394). Peer leaders, person with diabetes, are providing DSMS after completion of a DSME program. Researchers have found that the effects of DSME in community dwelling participants are not sustained after six months without continued support (Norris, Engelgau, & Narayan, 2001; Norris, Lau, Smith, Schmid, & Engelgau, 2002). Studies are ongoing to evaluate the effectiveness of peer leaders and community health workers (Tang et al., 2014)

Community participative or action research is well suited for research with the incarcerated population in that it involves all stakeholders in the process and is effective for reducing health disparities (Tapp, White, Steuerwald, & Dulin, 2013). The participants in the community in this case the prison identify the problem as well as strategies for solving their problems. Patient Centered Outcomes research, a more recent approach to participative research, actively solicits knowledge, experience, and goals of key stakeholders. The benefit of PCOR is that all stakeholders and researchers collaborate to make decisions that are fair and acceptable to all parties involved (Selby, Beal, & Frank, 2012). Conducting research with PCOR methodology in the correctional system would likely involve DOC administration, health care providers, nurses, and inmates. The drawback to PCOR for diabetes related research in state correctional systems might be in finding comparator groups.

The tenets of PCOR and CPR may seem at odds with prison rules often required for maintaining security and safety of inmates and staff. And using PCOR and CPR methodologies with inmates may seem contrary to the strict regimentation that is expected of inmates. However, some organizations that provide health care to inmates and DOCs are already in the process of engaging inmates in aspects of their care. For example, prison advisory groups have been formed; surveying inmate about satisfaction and health needs have become more

commonplace. Using PCOR and CPR research with inmates is a logical progression of these efforts. Engaging inmates in identifying problems and strategies for solving diabetes related problems would also likely increase their problem solving abilities and other skills needed for re-entry. Preferences for education, evaluation of different methods of delivery, effectiveness of different insulin and medication regimens on A1C, peer led education programs, safe glucometer use could all be examined with one of these participative methodologies. These research methodologies in and of themselves would serve as an intervention to improve inmates self-care behavior.

In closing, evidenced based diabetes care and clinical behavioral diabetes research are lacking. The research described in chapter one is the first to address factors affecting glycemic control in an incarcerated population. The findings from this research and lessons learned while conducting this research will provide a foundation from which to build effective interventions to improve SCB and glycemic control in incarcerated persons with diabetes. Rediscovering self-care for diabetes and all other aspects of behavior is essential for transitioning to the community, reducing recidivism and health care disparities in prison and in the community.

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